HealthRIGHT
Who We Are

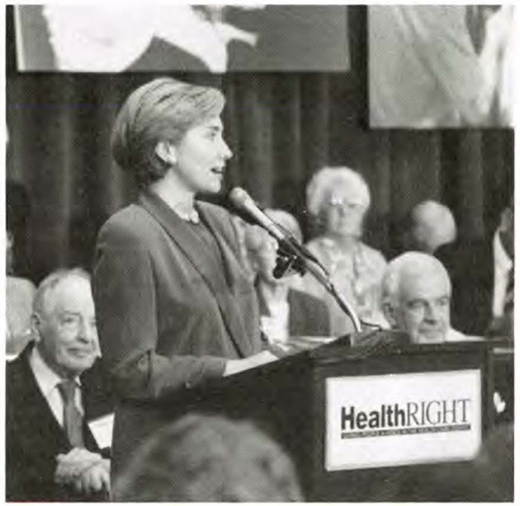
HealthRIGHT is a nonprofit coalition working for comprehensive and compassionate health reform, including long-term care.

Founded in 1992, HealthRIGHT unites organizations and individuals in a powerful coalition for change.

Just as the drug companies and the insurance industry have lobbyists in Washington, HealthRIGHT is the people's lobby. Our goal is to show Congress and the White House the human face of the health care crisis, while at the same time mobilizing the American people to press policymakers for meaningful health care reform.

HealthRIGHT
What We Do

HealthRIGHT is the first video petition for health care reform. The HealthRIGHT camera crew travels coast to coast collecting testimony from Americans concerned



about this critical issue. They conduct interviews in city halls, hospitals and hospices, senior centers, schools and shopping malls — anywhere people congregate.

In the summer of 1993, HealthRIGHT completed a 16,000-mile tour of all 50 states and the District of Columbia. Thousands of Americans spoke out about the health care system and what they thought should be done to improve it.

In January of 1994, HealthRIGHT brought one person from each of the 50 states and DC to Washington to present their stories of health care hardships to the US Senate. This unique event was described by Senator Harris Wofford (D-PA) as an "extraordinary presentation" that "every American needs to listen to and learn from." Subsequent Congressional events have brought 51 elderly persons to testify before the US House, and 51 children and their families to testify before the Senate. First Lady Hillary Rodham Clinton heard testimony and spoke at the senior citizens event.

HealthRIGHT
Why We Do It

Every major social reform in the United States — women's suffrage, Social Security, civil rights and Medicare, to name a few — has been preceded by a groundswell of public support. HealthRIGHT aims to harness the American people's strong desire for comprehensive health care reform in order to break through decades of gridlock and arrive at a workable solution. HealthRIGHT uses a three-pronged approach

- videotape, personal testimony and detailed survey data gathered from persons interviewed
- to enable the people to directly and powerfully petition their leaders for change.

HealthRIGHT
What You Can Do

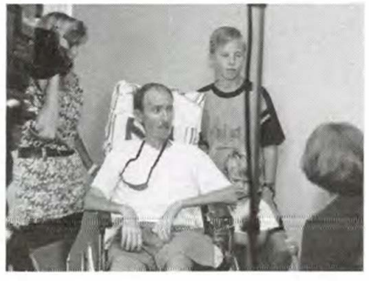
- Express your views on health care reform to your Senators or your Representative. Call the Capitol Hill switchboard at (202) 224-3121 and ask for them by name.
- Write a letter to the editor in your local newspaper, making the case for health care reform.

- Send your own videotape to HealthRIGHT. We will accept color videotapes, labeled with the name and address of the person/organization who prepared and submitted them. Please include the name, address and telephone number of each person who appears on tape. Videotapes submitted become the property of HealthRIGHT and cannot be returned.

- If you prefer, send a photograph of yourself or someone whose health care experience you want to share. Please attach a written explanation of the photographed person's experience and/or views regarding the health care system. Photos submitted become the property of HealthRIGHT and cannot be returned.
- Fill out a HealthRIGHT survey, which asks about your priorities for health reform and your personal experiences. To obtain a copy, call the HealthRIGHT office. Distribute copies to your family and friends.
- Call the HealthRIGHT office for more suggestions of how to get involved.

HealthRIGHT
505 C Street, NE
Washington, DC 20002
(202) 543-HELP

Among those interviewed by HealthRIGHT are, top to bottom, actor Michael J. Fox in New York City; a mother concerned about health reform, in Chicago, IL; native Americans living on the Yakima Indian Reservation, Yakima, WA; and an ALS patient and family, Woodland Hills, CA.



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GIVING PEOPLE A VOICE IN THE HEALTH CARE DEBATE
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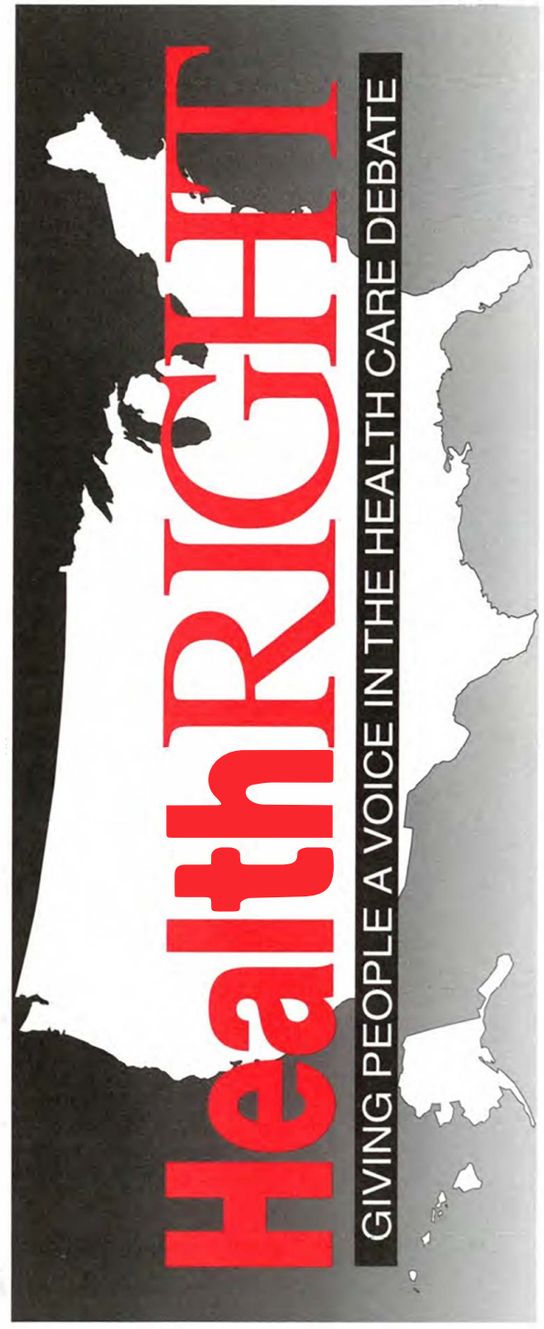

Health RIGHT

PHOTOCOPY
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HOMECARE™

NATIONAL ASSOCIATION FOR HOME CARE
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GENERAL COUNSEL

August 5, 1994

First Lady Hillary Rodham Clinton
Old Executive Office Building, Room 100
Washington, D.C. 20500

Dear Mrs. Clinton:

Thank you again for taking time from your busy day to participate in our latest HealthRIGHT event, which took place today in the Ways and Means Committee hearing room. From all reports things went extremely well. All of the networks, plus CNN and MacNeil/Lehrer requested a copy of the video petition, which we presented. We hope that the result, once again, will be positive news coverage which will help bring about the enactment of true national health care reform.

When I returned to the office I received a rude shock. Our staff obtained a copy of the Mitchell bill and analyzed it carefully. The conclusion of our staff and members of our Government Affairs Committee is that the bill is inadequate -- marginal at best in terms of meeting the objective for which we have all worked so hard, namely universal coverage. We have even more problems with the treatment home care receives in the acute benefits provisions. Although home health is included in the standard benefits package, it can only be used when required as an alternative to institutionalization.

Even more serious from our point of view are massive cuts in Medicare, a disproportionate share of which would come from home care beneficiaries. We are still analyzing the proposal, but as we understand it, it contains the following provisions:

- A 20 percent co-payment in the Medicare home care program would be required. This provision would be particularly devastating. It would cut the home care program by approximately $26 billion over a five year period. The burden of this provision would fall squarely on the shoulders of Medicare beneficiaries. Our members are concerned that this would add billions to their administrative costs at a time when their reimbursement rates are frozen or being reduced and that it will act as a significant disincentive to the use of home care benefits resulting in the end of increased program costs as individuals are kept longer then necessary in institutions.

- A continuation is proposed of an existing freeze on Medicare payments. Under current law, Medicare costs and related limits are updated each year with automatic increases put into effect which mirror increased costs related to inflation. Costs which have been frozen for the past two years would remain frozen at the 1993 level until July 1996.

- A reduction in the Medicare cost limits is proposed to 100 percent of the median. Costs limits are currently set at 112 percent of the mean. This is slated to reduce Medicare benefits by at least $4.2 billion over five years.

Unfortunately, the above information comes only one day after a report in the *Wall Street Journal* that the Clinton Administration has shifted $250 billion in future Medicare spending away from home health agencies to hospitals as a means of enlisting the support of the American Hospital Association, as one of the so called "Four Horsemen" allied to bring about health care reform.

I have been around this city long enough not to believe what I read in the newspaper, but our members are extremely alarmed. You have been gracious enough to say on several occasions that no group has worked harder in the crusade and support of the President's health care reform plan than has the hospice and the home care industry. I know this is where your heart lies. The National Association for Home Care and our allied Center for Health Care Law, Hospice Association of America and HealthRIGHT organizations have done everything possible to assist you and the President. As you know, we have spent millions of dollars in a national advertising campaign and funded HealthRIGHT as a means of bringing real people with real problems to Washington to lobby the Congress, to support the President and increase pressure for health care reform.

The measures which are now being proposed by some people in Congress, supposedly with Administration support, appear to be punitive and discriminatory to home care providers and the millions of people they serve. I hope that we are wrong and that there is some misunderstanding on our part. I would like to emphasize the gravity of this matter by telling you it threatens our very support of current health care reform legislation.

It is my fondest wish to be able to use all of our energies and resources in support of health care reform over these coming weeks. We have worked so hard to assist you and the President in pursuit of common objectives. We would be extremely reluctant now to have to oppose the legislation. I am writing to ask your advice on how to proceed. May I ask your staff to set up a meeting for us to resolve this matter at the earliest opportunity with key White House staff to discuss this matter? We are asking for similar meetings with members of Congress.

Sincerely,

Val J. Halamandaris
President

cc: Melanne Verveer

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HealthRIGHT

GIVING PEOPLE A VOICE IN THE HEALTH CARE DEBATE

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Health Security Express

Profiles

A nonprofit coalition for comprehensive, compassionate health reform

505 C Street, N.E., Washington, D.C. 20002-5809 • 202/543-HELP

HEALTH SECURITY EXPRESS PROFILES: WESTERN ROUTE

Matt Austin
Billings, MT

My name is Vonnie Austin. I'm here today with my 17-year old son Matthew, who has muscular dystrophy. (Matt will want to say a word himself when I finish.) We live in Billings, Montana. Matt is ambitious and independent and would like to become a lawyer someday. Right now, he's getting help with his medical costs from my private insurance and the Montana MD Association. He gets Medicaid but, in Montana, it won't help with home care so I handle my son's personal care. I want Matt to go to college and I know that's a dream of his. But where will he live? Who will care for him? And what will happen when he reaches the age of 21 and has to leave my insurance policy? With his pre-existing condition, he'll be virtually uninsurable for life.

Connie Bowen
Portland, OR

Connie Bowen, 71, was diagnosed with cancer, arthritis, and many other frail, elderly diseases that require an on-going need for costly prescription medications. During her work, she provides personal care assistance in the home and fears the day when she will leave such care because she has no funds for long-term care with her limited income. Additionally, her daughter died at home at the age of 27 from cancer. Having limited Hospice care, Ms. Bowen once again experienced the need for long-term care.

Violet Bronson
Yakima, WA

Violet's son died of AIDS in 1991 He worked for a company that offered health insurance. However, when he became too sick to work, his insurance was cut off. After her son's death Ms. Bronson created Care Bearers, a volunteer organization providing support services to people with AIDS and people who have tested positive for HIV.

Michelle Brown
Salt Lake City, UT

Michelle Brown is from Salt Lake City. Her husband died of AIDS last January. She is now volunteering on the State Commission on AIDS. They had to wait 2 years to qualify for Medicare, which still didn't cover any of her husband's medication or home care. For 3 months, the family was uninsured, which was difficult. She underscores the need for all people to have access to health insurance.

Larry Clifton
Paradise Valley, AZ

Our daughter was in a severe automobile accident in August 1991. She was in a coma for 7 months. Although her physical injuries have healed, we are working daily with a very slow, but progressing, brain injury recovery. We were then, and are presently, covered by Blue Cross/Blue Shield of AZ. During our year long stay in various hospitals and rehab centers our bills averaged more than $20,000 per month. Our insurance company refused to pay for the last 6 months of our stay at a licensed facility. We brought our daughter home with doctors prescriptions for Home Health Care. She is deaf, can't speak and takes her fluids and nourishment through a gastric tube. The insurance company, without ever seeing Keri, over our Neurologist orders for home nursing

has not paid $1 for home health care, even though we have been able to reduce Keri's cost of care by thousands of dollars per month. The insurance company has said they will pay for institutionalizing her which would cost 3 to 4 times what her care does now at home. We have physician prescriptions for durable medical goods that we have purchased on our own because of huge cost savings due to the long term nature of Keri's illness. I bought an electric hospital bed for $375 in near new condition. Blue Cross/Blue Shield said they would rent one for us as long as necessary, but would not pay for buying one. I checked with Blue Cross/Blue Shield providers only to find out rent would be $125 to $160 per month.

It is appearing that if Blue Cross/Blue Shield continues withholding the care Keri's physician has prescribed we will have to revert to state care provided by Arizona. We have tried not to do that since we have one million dollars of coverage on our Blue Cross/Blue Shield policy.

Deborah Dimmick
Grants Pass, OR

Mrs. Dimmick's husband Raymond has ALS, a devastating terminal disease that attacks the nervous system. The disease was misdiagnosed as a stress and fatigue syndrome. Raymond's physician recommended he change professions and environment to relieve the stress. The family of seven moved to Oregon and when they proceeded to reinsure themselves, Raymond was denied due to a pre-existing condition of hypertension. Subsequently he was diagnosed with ALS. The family has had to remain at the poverty level to qualify for limited medical assistance. The course of Raymond's disease requires long-term care. The family is struggling to care for him at home. He is presently confined to a wheelchair and unable to care for him at home. He is presently confined to a wheelchair and unable to assist with any of his activities of daily living. Universal coverage and long-term care would keep this family together and increase their quality of life.

Ted and Diane Durbin
Keizer, OR

Ted has disability insurance with Medicare, but it only covers a asmall portion and leaves him with extra out-of-pocket costs. He avoids going to the doctor even though he needs treatment for a thyroid condition. He tries to take care of his fanily with 4 children still living at home.

Marla Fetterhoff
Salem, OR

Marla's husband is blind. They manage an apartment full of elderly people. Both of them are uninsured because they employer will not provide insurance.

Arthur S. Flemming

HealthRIGHT Chairman Arthur Flemming is one of America's most respected and experienced public servants. For more than six decades, he has crusaded for health care reform, civil rights, retirement benefits and other public concerns, serving eight Presidents. Dr. Flemming was Secretary of Health, Education and Welfare under President Eisenhower. At various points in his career, he has also held the posts of U.S. Commissioner on Aging, Chairman of the U.S. Commission on Civil Rights and Chairman of the White House Conference on Aging. He is currently Chairman of Save Our Security, an organization dedicated to fighting arbitrary cuts in Medicare and Social Security. Dr. Flemming has received numerous honorary degrees and awards, including the Presidential Medal of Freedom. But this 89-year-old crusader would like no other reward for his decades of hard work than to see enactment of a comprehensive, compassionate health care program.

Jose Gomez Moreno
Wapato, WA

Mr. Gomez is a non-English speaking retired migrant farmworker. His employees never provided health insurance or other access to medical care. Mr. Gomez's kidney burst and was removed. He qualified for Social Security Disability after his surgery. Since he was unable to work, his wife and children supported the family. The social Security Administration suspended his disability benefits and medical assistance because the family was bringing in income. They went to court to get their medical coverage back and were successful. Mr. Gomez is currently receiving care at a community health clinic in Yakima. He is being followed for severe diabetes and hypertension, secondary to the loss of his kidney. He is legally blind.

Juanita Long
Salem, OR

Juanita Long's husband had congestive heart failure and emphysema. His condition weakened him to the point he was wheelchair-bound. With these ailments, he was in and out of the hospital repeatedly. "I was there so often visiting them," his wife reported, "that I thought the hospital would start charging me rent." When he was able to return home, Mrs. Long was her husband's full-time caregiver. A good portion of her time was spent administering the 60 or so pills he took each day. Mr. Long died in December of 1991. By then, almost all of the couple's savings had been depleted paying for health care costs that Medicare didn't cover. Mrs. Long now lives on a fixed income, with nothing set aside to take care of her should a long-term illness strike. "It really does scare me to think about it," she said. "If that happened, I guess I'd have to sell my home."

Donna Milota
Santa Clarita, CA

Donna is the mother of 29-year-old Jay Milota who was infected with Multiple Sclerosis at the age of 25. At that time, his Blue Cross insurance premium was $100 per month and has skyrocketed to over $275 per month. Without working, he couln't afford to pay his premium, no could his mother. Currently he is uninsured because he was forced to drop his insurance coverage. His mother is his full-time caregiver and retired with limited income.

Juliena Milota
(same as mother's)

Juliena has post-traumatic depression and requires outpatient therapy on a regular basis, with only 50% of the costs covered. To date, her bills have accumulated to over $1,500-$2,000 since January, 1994. Her mother has used her limited income to try to stay on top of these huge medical bills. Aetna covers Juliena now but once she turns 18 she fears being denied for pre-existing condition.

Anita Monoian
Yakima, WA

Ms. Monoian is Executive Director of Yakima Neighborhood Health Services, a non-federally funded (330/329) community clinic serving about 500 patients and clients per day. Our community is roughly 100,000 with a mix of rural and urban. Our economy is largely agricultural, creating a clientele for our organization of migrant/settled out migrant/working poor non-argricultural related.

Also President of Northwest Regional Primary Care association, and currently serving on the Public Health Improvement Plan for the state of Washington, a committee mandated by the

Washington Health Care Reform Service Act of 1993. The PHIP is charged with drawing the "blueprint" for improving health status in Washington through prevention and improving capacity for public health service delivery by addressing three main goals:

1.Control health systemn costs.
2. Ensure universal access to needed health services for all state residents.
3. Improve the health of the state's population.

Additionally, she is the mother of 3 children who as they graduate from college are suddenly uninsured.

Mary Rose Oakar

The Honorable Mary Rose Oakar, President of HealthRIGHT, served Ohio's 20th District in the U.S. Congress from 1977 to 1993. Throughout her tenure in the House, this former Cleveland City Councilwoman distinguished herself as an unwavering advocate for a fair and compassionate national health care policy for all Americans. In 1989, Ms. Oakar was appointed by the Speaker of the House to the U.S. Bipartisan Commission on Health Care Reform, also known as the "Pepper Commission." She was also a senior member of the House Select Committee on Aging, where she championed such causes as breast cancer detection, prevention and treatment and prevention of elder abuse. Now head of her own public relations firm, Oakar and Associates, Mary Rose Oakar continues to pursue such issues as women's economic and health equity, geriatric research, retirement income security, Middle East peace efforts and, of course, health care reform.

Georgia Sandoval
Wapito, WA

Violet is the youngest daughter of Jose Gomez. She is a medical office manager and has worked in a community health center in Yakima for the past 13 years. She is an advocate for disadvantaged members of her community who need assistance getting through the medical mainstream. Georgia is the key support and health advocate for her parents.

John Van Slyke
Eugene, OR

John Van Slyke is a small businessman from Eugene, Oregon. He wishes to provide health insurance to all of his employees but has not been able to find an insurer who will cover those who have pre-existing condition. "The problem is the issue of cost control and having the insurance be affordable, and having it available to all of my employees, regardless of their pre-existing health conditions," ways Van Slyke. "I know I'm going to have to pay more to do it, and I'm willing to do that, absolutely, if the plan really does the job that it's supposed to do and that it provides good preventive health care and covers everybody."

HEALTH SECURITY EXPRESS PROFILES: MID-WEST ROUTE

Irma Martin
Olathe, KS

Ms. Martin is full-time caregiver of her mother-in-law, Patricia Martin age 60, who is inflicted with Multiple Sclerosis. Patricia has lived with Irma for 9 years. Patricia is confined to a wheelchair and requires long-term home care care since Medicare has limited coverage. There is no relief for full-time caregivers and no coverage for prescriptions. Patricia is losing the function of one kidney without an essential procedure. Since Medicare covers only 80% of this procedure, it will leave the family financially devastated. In addition, they still have ouitstanding bills from the last procedure.

Eugene Sims
Kansas City, MO

Eugene suffers from cancer in the jaw and high blood pressure. He has Medicare and was forced to "spend-down" to $423 per month in order to receive coverage from Medicaid to cover the costs of his prescription drugs.

B.J. Renfrow
Fairway, KS

BJ is a self-employed individual. BJ's son, Duncan Rentrow-Symm, was born on 2/10/89. He has chronic asthma. Her son's severe asthma condition limits him to the home environment. Her son's illness accumulated $30,000 in costs until he started on Medicaid 6 months ago. However, Medicaid limits home care.He had previously been insured by Blue Cross/Blue Shield, but his premiums increased from $99-$469 with less coverage. Bj had to drop the insurance.

BJ'swas also her grandmother's caregiver. Her grandmother died of heart failure at home. She was covered under Medicaid, but most of her home care was not covered.

DeLana Marie Shipley
Lansing, KS

Cancer of the spine-lumbar section removed. It left her partially paralysed in 1981. There family insuarance is an HMO , which covered only 80%. There out of pocket expense is now $500. Their family premium is $485 per month and increasing. They are a one-income famuily. Her husband's salary s a school teacher is limiting, making the premium difficult to meet. We need some type of affordable coverage. She must choose whether to but her family their belongings or pay the insurance premiums-or spend it all on a wheelchair.

HEALTH SECURITY EXPRESS PROFILES: CENTRAL ROUTE

Richard Ross
Hallsville, TX

Richard was a meatcutter for Winn Dixie and was covered through his job. He started experiencing joint pain, and found that he couldn't stay awake for his 12 mile drive home after work. After about $10,000 worth of tests, the doctors diagnosed him as having Chronic Fatigue Syndrome. He had to quit his job to receive treatment, and was terminated from his health insurance coverage a year later. He got COBRA for awhile, but eventually had to drop it because it was too expensive for his family to afford. He was then diagnosed with lymphoma and had to receive radiation treatments. Eventually he got social security disability insurance, but his family still has very minimal coverage. He says no insurance companies will even talk to him since he has had cancer. He is frustrated because he has spent his entire life paying for insurance, and when he actually needed help from the insurance company, it deserted him.

Linda Phillips Thune
Austin, TX

My husband, Peter and I have five daughters. Four have Asthma, as do I, one has insulin-dependent diabetes, and another lost her hearing due to a viral infection at 9 months old. We both moved to Colorado in 1973 and had hoped to spend the rest of our lives there. My husband was fortunate to be hired by IBM in 1986. IBM, literally saved our lives -- the medical benefits are so essential to the well-being of our whole family, that when the plant in Colorado Springs closed, we had to transfer with IBM to Austin, TX. We are very grateful to IBM -- we have hundreds of dollars each month in prescriptions and doctor visits. We are able to provide a good life to our daughters due to the benefits we receive through IBM. Although we do live paycheck to paycheck, we have had to pay an additional $80.00 monthly to keep our major medical plan which offers choice of doctors, hospitals, prescription reimbursement at 80%, etc. When a family has as many medical needs as we do; i.e., ENT specializing in cochlear implants, pediatric nephrologist and endocrinologist, etc., it is vitally important to have choice of doctors that we can have a close relationship and feel very comfortable with. Our 20% co-payments can still be quite a burden -- so I feel it is unfair that if a family needs choices, they have to pay more to do so. The medical conditions warrant the use of specialists in many families like mine. We are already having to pay a great deal more for therapies, medications, etc.

I pray each night that Peter survives the seemingly routine job cuts at IBM and that we don't have to transfer again in order to keep benefits. Without our health benefits, our family would fall apart.

Peggy Sackett
Austin, TX

Peggy, 36, was injured working. She got freon gas poisoning while working for a temporary agency. An employee of the industry, turned on a machine that released freon vapors into the air. She now has respiratory airway dysfuction syndrome (RADS), occupational asthma, and environmental asthma. She is totally disabled. She is currently fighting to keep her home, because she and her husband are running low on funds. Her insurance will only pay up to 5 years of her medical bills. She will be disabled for the rest of her life due to this accident. Her husband works at Sam's Club. Her husband's company is trying to take away his health care benefits. She is not covered by Medicaid or Medicare.

Mary Crain
Austin, TX

Mrs. Crain had gall bladder surgery several months ago. She had to pay for the surgery out of pocket because she has no health insurance. Her husband owns a small business- he is a cement contractor. He has no health insurance for himself or his family through his job. They can not afford to pay the premiums for private insurance. Mr. and Mrs. Crain have been uninsured all of their lives. Mrs. Crain is not old enough to qualify for Medicaid, or Medicare.

Diane Crawford Merrill
Ada, OK

Ms. Merrill turns 21 years of age this year at which time she will be taken off her father's insurance policy. She will have no coverage after that point. She is in desperate need of an operation on her knee but cannot have the operation due to lack of insurance.

Geneva Howard
Jack C. Howard
Ada, OK

Diagnosed in 1990 but developed symptoms in 1967 when first encountered problems walking. Husband diagnosed in 1992 with multiple sclerosis which doctors say is possibly due to environmental exposure during military assignments. Husband and wife have CHAMPUS; she is on Medicare. CHAMPUS covers 75% of needs but the 25% out of pocket costs came to $300 each month for prescriptions only. Mr. & Mrs. Howard should be taking a drug which would cost an additional $500 each month. They cannot afford to pay for this additional medication.

HEALTH SECURITY EXPRESS PROFILES: SOUTHERN ROUTE

Debbie Clay
Chattanooga, TN

Debbie has chronic SLE-Lupus. She fears losing her health care coverage. Because of her condition she is forced to pay astronomical premiums. She is also concerned that if she loses her coverage so will her 25 employees.

Yvonne Rogers
Metarie, LA

Mrs. Rogers' husband has had two open heart surgeries. He recently started his own business, and has very little health insurance coverage. The company that he used to work for squeezed him out of his health insurance coverage and left him with high medical bills. Mrs. Rogers' sister has extremely high medication costs which she can not afford to pay for herself. She leaves the air conditioning off frequently to save money for her bills. Several of Mrs.Rogers' nieces and nephews can not afford insurance and make too much to go on Medicaid. Her son recently went to a charity hospital to receive treatment for a broken jaw because he was between jobs, and had no health insurance. She says she has a very large family, many of whom are facing problems with the health care system. She has much to talk about.

Mitzi Barker
Ooltewah, TN

Ms. Barker was laid off from her job and could not afford the health insurance premium when it was shifted from group to a self-pay policy of $1,000 per month. Ms. Barker could not afford this, so she went without insurance for 5 1/2 months. During that time she became severely ill with a bacterial infection, which closed her respiratory track and required at least four emergency room visitis and five doctor visits. Her total, including prescription drugs, came to over $6,000. This has caused her family severe fianancial hardship.

Helen Vicknair
Kenner, LA

Helen is 75 years old and has had asthma almost all her life. She must use a pump to assist her with her breathing. She also has high blood pressure and an inner ear problem requiring her to take seven kinds of medication which are very expensive. She has large medical bills which her insurance does not cover. She requires a wheelchair.

Cecele Centanni
Kenner, LA

Cecele is 75 years old and has high blood pressure. She must make sacrifices to meet her medical insurance costs. She lives at home and would like to see long-term care coverage for people like herself.

Mary Miller
Kenner, LA

Mary is 75 years old. She has high blood pressure, a heart condition, a thyroid problem and is blind in one eye, with sight rapidly deteriorating in the other eye. She also has high medical bills

which her health insurance does not cover. These costs are skyrocketing and she does not know how she will be able to continue to pay for the insurance she needs.

Sonia Falcon
Chalmette, LA

Sonia has been in home care for fourteen years. During her tenure as a nurse she realized that the best, most cost effective care for clients needing long term care was in a home setting. Keeping our seniors in familiar surroundings and creating an environment to administer preventative care preempiting reccurring hospital stays is great for the client and the system by containing costs.

In addition to serving our seniors with long term care, Sonia sees a real need for long term care at all phases of life. Louisiana is one of the highest states in the union for premature births and infant mortality. Sonia has seen the tremendous need for long term care should as part of the continuum of care from cradle to grave.

Sonia's family is currently uninsured because of a recent job change. With a preexisting health condition for one of her two children her insurance premium would be $475 per month.

As a small business owner she would like to see affordable insurance for not only herself, but her employees as well; insurance premiums that would not break the back of her new business.

HEALTH SECURITY EXPRESS PROFILES: NORTHEAST ROUTE

Peter and Quincy Sherman
Little Campton, RI

Quincy is 6-years-old. Her father, Peter Sherman is self-employed and his wife, Christie is unemployed. They cannot afford medical insurance. They have a choice of providing medical insurance or putting food on the table. A few weeks ago, a pre-screening routine was required for Quincy to be admitted to school. To keep the cost down, her mother took her to a walk-in clinic which wanted her to pay $68. She refused and went to another clinic where they wanted her to pay $65. Mrs. Sherman had to tell the school she was unable to have the pre-screening done, so Quincy was unable to be admitted to school. The school found the local VNA which provided the pre-screening on a sliding scale, charging the Shermans just $10. The Shermans have two daughters, ages 8 and 6 and must wait until they are extremely ill to see a doctor. Their other daughter has scarring on her ear drums and was beginning to experience difficutly hearing as a result of numerous untreated ear infections. This type of frustation, being unable to afford basic health care, causes the Shermans to choose between obtaining health care or putting food on the family's table.

Douglas Eaton
Gorham, ME

Mr. Eaton, 51, is a self-employed individual who has difficulty affording insurance premiums. His monthly premium is appromately $124, and is expected to increase in August. The insurance he receives does not cover his needs. Additionally, he is fearful that if he requires serious care in the future, he does not have the means to acquire it.

Linda Dare
Tigarol, OR

Linda's husband, Matthew Dare, had to undergo a kidney transplant. A year and a half ago. He lost his COBRA insurance and for six months he paid for private insurance as well as paying for his prescription drugs. After a period of time he became eligible for Medicare due to his disability. By this time, he had accummulated between $30,000-$40,000 per year in medical costs. Currently, Mr. Dare must do without certain medications due to the prohibitive costs.

Nancy Denofio
Manchester, NH

Nancy, 44, has multiple sclerosis, is legally blind, and is completely disabled. She has had many problems with her HMO in New Hampshire because it will not cover the expense of her maintenance therapy mediation which is $139 per month. Two years ago, she moved from New York, when her husband changed jobs. Her medication was covered under her previous HMO through her husband's job in a large corporation. Now that he works for a smaller company, she must pay out of her own pocket for the medication that she needs. Her husband was unemployed for a few months while he looked for a new job, and they are currently finacially strapped. She needs a new wheelchair in order for her chronic condition to improve, but she can not afford the $2600 up front that it will cost. 3 doctors have ordered the wheelchair, deeming it medically neccessary, but her Medicare disability insurance will not pay for any "durable medical equipment," and excludes her from other benefits because of her age. She thinks that it is ironic that if she entered a rehabilitation center, she would immediately receive the wheelchair, when the cost to the American people of her stay in the center *and* the wheelchair is clearly more than simply

the wheelcahir itself. She has already been contacted by Hillary Clinton's office- they want to use her story in an upcoming speech by Mrs. Clinton. (Nancy wrote to the White House with her story). Nancy is also a published writer, and has written numerous articles for Network, an international women's magazine. She is irritated with the health care system, and wants an opportunity to tell her story to the Congress and the Clintons. Nancy contacted *us* when she heard of our activities.

Maureen Michael
Manchester, NH

Maureen Michael has been unemployed for over a year. At the end of her employment cycle she was given severnace pay and COBRA, but is still responsible for a $204 out-of- pocket monthly expense for her insurance. Her COBRA supplements will end in January of 1995, at which time she will be completely uninsured. Unfortunately, this means not being able to attend to medical needs that cannot be ignored.

After noticing her eyesight was diminishing rapidly, Maureen was diagnosed with glaucoma. As with many illnesses, the glaucoma was not diagnosed early, and other conditions resulted further hindering her eyesight and requiring additional care, including hospitalization. In addition to health problems caused by the glaucoma, Maureen suffers from depression and anxiety. All these conditions require costly medication that place a tremendous strain on the family and on its finances.

Maureen would like to return to the work force. Unfortunately, with her preexisting health conditions she would be ineligible for most plans any employers can currently afford to offer.

HEALTH SECURITY EXPRESS PROFILES: WASHINGTON, D.C.

Mildred Hamilton
Chattanooga, TN

Mrs. Hamilton is a quadriplegic who needs round-the-clock care. Although she has Medicare and Medicaid, this coverage is still not enough. For example, since January her out-of-pocket expenses have exceeded $7,000 for her medical supplies, and she is about to lose her coverage for physical therapy. In addition, her husband would like to get a full-time job but is unable to work because he stays home to care for her.

Long-term home care is an essential part of health care reform so he can go to work and be sure her health care needs are attended to.

PROFILES OF REFORM RIDERS WITH SPEAKING ROLES

B.J. Renfrow (Midwest Route)
4300 Brookridge
Fairway, KS 66205
913-384-9122

BJ is a self-employed individual. BJ's son, Duncan Rentrow-Symm, was born on 2/10/89. He has chronic asthma. Her son's severe asthma condition limits him to the home environment. Her son's illness accumulated $30,000 in costs until he started on Medicaid 6 months ago. However, Medicaid limits home care.He had previously been insured by Blue Cross/Blue Shield, but his premiums increased from $99-$469 with less coverage. BJ had to drop the insurance.

BJ was also her grandmother's caregiver. Her grandmother died of heart failure at home. She was covered under Medicaid, but most of her home care was not covered.

Michelle Brown (Western Route)
1750 Yale Avenue
Salt Lake City, UT 84108

Michelle Brown is from Salt Lake City. Her husband died of AIDS last January. She is now volunteering on the State Commission on AIDS. They had to wait 2 years to qualify for Medicare, which still didn't cover any of her husband's medication or home care. For 3 months, the family was uninsured, which was difficult. She underscores the need for all people to have access to health insurance.

Matt Austin (Western Route)
1724 Alderson
Billings, MT 59101

My name is Vonnie Austin. I'm here today with my 17-year old son Matthew, who has muscular dystrophy. (Matt will want to say a word himself when I finish.) We live in Billings, Montana. Matt is ambitious and independent and would like to become a lawyer someday. Right now, he's getting help with his medical costs from my private insurance and the Montana MD Association. He gets Medicaid but, in Montana, it won't help with home care so I handle my son's personal care. I want Matt to go to college and I know that's a dream of his. But where will he live? Who will care for him? And what will happen when he reaches the age of 21 and has to leave my insurance policy? With his pre-existing condition, he'll be virtually uninsurable for life.

*alternate

Nancy Denofio (Northeast Route)
319 Circle Rd.
Manchester, NH 03103
(603) 644-4372

Nancy, 44, has multiple sclerosis, is legally blind, and is completely disabled. She has had many problems with her HMO in New Hampshire because it will not cover the expense of her maintenance therapy mediation which is $139 per month. Two years ago, she moved from New York, when her husband changed jobs. Her medication was covered under her previous HMO through her husband's job in a large corporation. Now that he works for a smaller company, she must pay out of her own pocket for the medication that she needs. Her husband was unemployed

Richard Ross (Central Route)
Rt. 3, Box 178
Hallsville, TX 75650
(903) 668-1069 (H)

Richard was a meatcutter for Winn Dixie and was covered through his job. He started experiencing joint pain, and found that he couldn't stay awake for his 12 mile drive home after work. After about $10,000 worth of tests, the doctors diagnosed him as having Chronic Fatigue Syndrome. He had to quit his job to receive treatment, and was terminated from his health insurance coverage a year later. He got COBRA for awhile, but eventually had to drop it because it was too expensive for his family to afford. He was then diagnosed with lymphoma and had to receive radiation treatments. Eventually he got social security disability insurance, but his family still has very minimal coverage. He says no insurance companies will even talk to him since he has had cancer. He is frustrated because he has spent his entire life paying for insurance, and when he actually needed help from the insurance company, it deserted him.

Mildred Hamilton (Southern Route)
1315 W. 46th
Chattanooga, TN 37409
(615) 821-4620 (H)

Mrs. Hamilton is a quadriplegic who needs round-the-clock care. Although she has Medicare and Medicaid, this coverage is still not enough. For example, since January her out-of-pocket expenses have exceeded $7,000 for her medical supplies, and she is about to lose her coverage for physical therapy. In addition, her husband would like to get a full-time job but is unable to work because he stays home to care for her.

Long-term home care is an essential part of health care reform so he can go to work and be sure her health care needs are attended to.

SCHEDULE FOR HILLARY RODHAM CLINTON
DATE: FRIDAY, AUGUST 5, 1994
FINAL

Lead Advance HealthRIGHT Event:
Brian McPartlin **WHCA Pager**

Scheduling Desk: **Julie Hopper**
202-456-7561 **office**
202-456-2317 **fax**
202-387-6842 **home**
1-800-528-7528 **WHCA #4096**

PREV RON The White House

9:00 am-
9:15 am **PVT MTG** w/Maggie Williams & Patti Solis
Residence

9:15 am-
9:30 am **PVT MTG** w/Maggie Williams
Residence

9:35 am **DEPART** The White House South Portico
EN ROUTE Capitol Hill
[Drive Time: 15 minutes]
Travelling w/HRC:
- Kelly Craighead
- Karen Finney or Neel Lattimore
- Melanne Verveer
- Liz Bowyer
- Sara Grote
- WH Photographer

9:50 am **ARRIVE** Longworth Bldg

NOTE: Brian McPartlin will meet HRC curbside.

Curbside Greeters: Werner Brandt - House Sergeant of Arms
Cong. Sam Gibbons
Cong. Kweisi Mfume

9:55 am **PROCEED TO HOLD**
Anteroom

NOTE: HRC will meet up with the remaining Congressional Members at this time.

10:00 am-
11:15 am **HealthRIGHT EVENT**
1100 Longworth Bldg, Ways and Means Committee Room
HRC's Holding Room: Anteroom
Phone: 202/225-3847 or 225-2690
Fax: 202/225-2610 Room 1102
OPEN PRESS

PARTICIPANTS: Approx. 250 expected to attend
[See briefing book for further info]

Seated behind HRC: Approx. 30 Health Security Express Reform Riders and families.

FORMAT:
- Arthur Flemming gives welcoming remarks

- HealthRIGHT Video presentation (8-minutes)

- Former Cong. Mary Rose Oakar gives [1-min] remarks and intros first member of Congress

* Each of the following Cong. Members will give 3-min remarks:
    * Cong. Sam Gibbons
    * Cong. Kweisi Mfume
    * Cong. Ron Wyden
    * Cong. Pat Williams (Tentative)
    * Cong. David Bonior (Tentative)
    * Sen. Ted Kennedy (Tentative)

- Five Health Security Express Reform Riders speak (2-minutes each -- List to follow)

- Speaker Thomas Foley gives brief remarks and intros HRC

- HRC gives remarks

- Exit stage right and work ropeline

Event Contact: Ron Kolanowski 202/547-7424

11:20 am **DEPART** Capitol Hill
EN ROUTE The White House
[Drive Time: 10 minutes]

11:30 am **ARRIVE West Executive Ave.**

11:35 am **PROCEED** to OEOB

11:35 am-
11:45 am **DROP BY** w/Correspondence Volunteers and Interns
Room 17 and 18, OEOB
CLOSED PRESS

PARTICIPANTS: Approx. 30 expected to attend

FORMAT:
- Official photo and meet/greet. **NOTE:** Volunteers will be in both rooms due to space limitations.

NOTE: WH Photographer will be present.

Staff Contact: Alice Puskar 456-5955

11:50 am **PROCEED** to Room 459, OEOB

11:55 am **BRIEFING For Conference Call**
Room 459, OEOB

Staff Contact: Julia Moffett

12:00 pm-
12:45 pm **CONFERENCE CALL** w/Letter Writers
Room 459, OEOB
LIVE SATELLITE FEED -- WH PHOTO

PARTICIPANTS:
- 5 Letter Writers from South Carolina, North Dakota, Wisconsin, Alabama, California
[See briefing book for more info]

FORMAT:
- HRC makes opening remarks
- HRC speaks to each letter writer individually
- HRC makes closing remarks

Staff Contact: Julia Moffett 456-5690
Josh Silverman 456-7150

1:00 pm-
1:20 pm **INTERVIEW For Mutual Broadcast Radio**
Interview conducted by: Peter Maer
Room 100, OEOB - Conference Room
CLOSED PRESS / ONE-ON-ONE LIVE TO TAPE

Staff Contact: Lisa Caputo 456-2960

1:30 pm-
1:40 pm **DROP BY**
Map Room
CLOSED PRESS

NOTE: WH Photographer will be present.

Contact: Mary Ellen Shattman 456-2566

1:40 pm-
2:00 pm **LUNCH**

2:00 pm-
2:45 pm **PRIVATE MEETING**
Map Room
CLOSED PRESS

Staff Contact: Lisa Caputo 456-2960

3:00 pm-
3:45 pm **PRIVATE MEETING**
Map Room
CLOSED PRESS

Staff Contact: Lisa Caputo 456-2960

3:45 pm-
4:45 pm **OFFICE/PHONE TIME**

4:45 pm **DEPART** White House South Lawn [w/the President]
EN ROUTE Camp David
VIA Marine One
[Flight Time: 30 minutes]

5:15 pm **ARRIVE** Camp David

RON Camp David, MD

WEATHER FORECAST FOR WASHINGTON, DC & CAMP DAVID, MD:
- Mostly cloudy with isolated afternoon thunderstorms. Wind southwest at 10 to 15 knots. Low 72 to 77. High 90 to 95.

CHOICE

Universal Reform Will Mean More Choice

- Under the House and Senate bills, all Americans will have a choice of insurance plan and doctor. People will be able to shop for the best coverage at the best rate -- because there will be more competition in the marketplace.

- People who are happy with their current insurance plans and doctor can keep them.

- Universal reform will protect the doctor-patient relationship. That's one reason why groups such as the American Medical Association, the American Nurses Association, the American Academy of Family Physicians, the American Academy of Pediatrics and the American Hospital Association -- the nation's leading provider groups -- support a universal approach.

- Today, more and more Americans are being forced into insurance plans where they are separated from their doctor. And most Americans have little or no choice of insurance plan.

The Republican Alternatives Offer Some Unattractive Choices

- Under the Dole plan, a family of four that makes $30,000 has the choice of spending nearly $6,000 -- 19% of their income -- for health insurance or having no insurance at all. (National Journal, 7/16/94)

- The insurance companies can choose to charge older workers as much as four times more than younger workers.

- Employers can choose to drop employees' coverage or cut back benefits.

Attached is a fact sheet that describes choice under the current system and under the House and Senate universal approaches.

CHOICE OF HEALTH PLAN AND DOCTOR

CHOICE TODAY

Eighty-five per cent of Americans believe that having a choice of doctor is "important" or "very important." (Gallup Poll/Consumers Union, April 20, 1993).

But, each year, fewer and fewer Americans are in health plans that give them full choice of doctor. And most Americans have little choice in health plans.

- Eighty-two per cent of employers of less than 50 employees offer their employees **no** choice of health care plan. (Kaiser Family Foundation, Peat-Marwick KPMG poll, July, 1994)

- Over 64% of employers with 50-1000 employees offer their employees **no** choice of health care plans. (Ibid).

- Almost two-thirds of employees (64%) are now in managed care plans that limit their choice of doctor to some degree. (Ibid).

- The number of Americans in managed care plans is increasing every year. The number in traditional fee-for-service plans is decreasing every year. (KPMG Peat Marwick, 1993 survey).

- Thirty-five per cent of employees no longer offer a fee-for-service plan. (KPMG Peat Marwick survey, 1993).

"Choice of health insurance plans, doctors, and hospitals is disappearing for many Americans. The question is not whether health reform will take choice away, but whether it will give it back." Drew Altman, President, Kaiser Family Foundation.

CHOICE TOMORROW: THE HOUSE AND SENATE PLANS

All Americans have the option to choose a health plan with full, unrestricted choice of doctor. All Americans have a choice of health plans.

Virtually every American who is satisfied with the health plan can keep that plan. Those who don't like their plans can choose another. And, unlike today, changing jobs will not usually require a change in health plans or doctors.

CHOICE IN THE HOUSE LEADERSHIP PLAN

- Large employers (over 100 employees) must offer at least two health plans, including a managed care plan and a traditional plan.

- Small employers (under 100 employees) have three options:

  1. Offer employees a choice of two plans, including a fee-for-service plan, and the option to enroll in the federal employee health benefits plan (FEHBP).

  2. Enroll their employees in the FEHBP.

  3. Enroll their employees in the new Medicare Part C.

- Both the FEHBP and Medicare Part C must offer managed care and fee-for-service plans.

- Additionally, all employers may offer a plan with a high deductible and a medical savings account.

- Those not connected to the work force, part-timers and seasonal employees enroll in Medicare Part C.

CHOICE IN THE THE SENATE LEADERSHIP PLAN

- Employers of over 500 employers must offer at least three plans, including a managed care plan, a point of service (POS) plan, and a fee-for-service plan.

- Employers with less than 500 workers must offer employees a chance to enroll in a purchasing cooperative; they may also offer plans directly. (All purchasing cooperatives must offer a fee-for-service plan, a health maintenance organization (HMO) and a point of service plan).

- FEHBP will contract with or offer a purchasing cooperative in every area. Workers in firms with less than 500 employees, those not connected to the work force, AFDC recipients, and the self-employed may purchase insurance through an FEHBP purchasing cooperative.

The Washington Times

Clintons' legal fund challenged in court

By Paul Bedard
THE WASHINGTON TIMES

Potential legal headaches for President and Mrs. Clinton increased yesterday when a public interest group sued the first family's legal defense fund, demanding that it close shop and return donations.

Judicial Watch — a nonprofit, nonpartisan group — charged in papers filed in U.S. District Court that the Presidential Legal Expense Trust violates several rules governing gifts to federal officials and secret meetings of presidential advisory committees.

In its papers filed before U.S. District Judge Royce C. Lamberth, the group said that "persons donating money to the trust . . . do so with the expectation that they will receive in return influence, political favors or something else of equal value from the executive branch, the president and/or Mrs. Clinton."

While the trust has been cleared by federal ethics officers, Judicial Watch, which is run by international trade lawyer Larry Klayman, said the fund damages the "integrity" of the presidency, harms "public trust" in the government and "works to the detriment of those citizens who choose not to be solicited and/or donate to the trust."

The suit papers charge that the defense fund is a federal advisory committee covered by the Federal Advisory Committee Act, which requires presidentially appointed panels not composed "wholly" of federal employees to meet publicly. The act was designed to prevent special interests from influencing the government in secret.

The fund's trustees include several government outsiders but operates in secret. But it is not clear if it provides any advice to the White House.

"We want it shut down," Mr. Klayman said.

The fund was set up in late June as the Clintons faced legal bills nearing $1 million over Whitewater and the sexual harassment suit filed against Mr. Clinton by Paula Corbin Jones, a former Arkansas state employee.

A $1,000 limit was set for donations, and solitications for contributions were planned for the fund run by trustees who are not government employees.

Plans to solicit money were dropped amid complaints from House Republicans.

Michael H. Cardozo, executive director of the Clintons' defense fund, said in an interview that the advisory committee act does not apply to his panel.

"I'm confident we are not a federal advisory committee. We don't meet the definition," said Mr. Cardozo, who had not seen the suit.

He added, however, that to fight the suit, the fund will probably have to spend its own money.

Meanwhile, two Republican lawmakers sharply questioned a review by the federal Office of Government Ethics (OGE) that cleared the defense fund even though the review was not requested until after the fund had been established.

Reps. Deborah Pryce of Ohio and C. Christopher Cox of California raised a "number of grave legal and ethics questions" in a four-page letter to OGE Director Stephen D. Potts.

The two Republicans suggested in the letter that the initial ethics review of the unprecedented presidential defense fund was inadequate and asked for a new review.

The lawmakers made two key points:

- The fund was set up to solicit cash gifts despite restrictions on gifts to presidents other than those relating to "protocol and etiquette." Those types of gifts are normally given by foreign governments.
- The fund allows lobbyists to contribute, raising questions of the political benefits expected by the groups.

"Even lobbyists will be permitted to pay the president's personal legal expenses," Mrs. Pryce and Mr. Cox wrote. "We therefore ask you to opine specifically on the contribution of money to the trust by lobbyists and others who may have an interest in influencing the president or gaining favor with him."

Mr. Cardozo said the fund no longer solicits money and simply waits for checks to arrive from Americans who have seen the trust's special address — Presidential Legal Expense Trust Fund, Dept. 70, Washington, D.C. 20055-0070.

Suit over Hillary's panel might be settled

ASSOCIATED PRESS

The Clinton administration said yesterday it will enter talks aimed at settling a lawsuit over whether it must publicly release the records of its 1993 health care working group.

U.S. District Judge Royce C. Lamberth ruled last month that the case must go to trial. He issued an order yesterday that said the two sides will hold a private settlement meeting in his chambers this afternoon.

Kent Masterson Brown, attorney for the three organizations challenging the health care group's secrecy, had said he might call Hillary Rodham Clinton and White House adviser Ira Magaziner as witnesses in the case.

Mrs. Clinton and Mr. Magaziner led the 500-plus-member working group's deliberations that resulted in the president's health care plan now before Congress. The working group met from January through May 1993.

Judge Lamberth said July 25 that factual disputes over the working group's makeup must be resolved in a non-jury trial.

"The administration has determined that it would be better to enter settlement discussions so that the officials involved can devote themselves to the business of passing health care reform," the Justice Department said in a statement yesterday.

The Justice Department said the administration believes it would win if the case were brought to trial.

"I have no objection, obviously, to hearing what they have to offer," Mr. Brown said. "If we feel it is not enough, then we will go on" to trial.

The Association of American Physicians and Surgeons, the American Council for Health Care Reform and the National Legal Policy Center are seeking hundreds of thousands of transcripts, drafts, minutes and other documents.

The three organizations contend federal law requires any such group to meet in public if it includes non-government members who may have their own private agendas.

Government lawyer Mark Stern argued at the July 25 hearing that the working group was too loosely structured to be covered by the federal advisory panel law.

In July, Judge Lamberth also deferred a decision on whether Mr. Magaziner should be held in contempt of court. The three organizations contend he lied in a March 1993 affidavit when he said all members of the working group were either government employees or consultants. Government lawyers have said Mr. Magaziner's statement was true at the time.

The allegations against Mr. Magaziner "are totally baseless and [the administration is] confident that any further proceedings will confirm this fact," the Justice Department statement said.

Judge Lamberth's order said he had authorized attorneys in the case to disclose the fact that settlement discussions would be held, but that the content of the discussions would be confidential.

The two sides had a preliminary discussion yesterday in Judge Lamberth's chambers, but Mr. Brown said government lawyers have not yet made a substantive proposal.

, AUGUST 5, 1994
The Washington Times

Health reform forced on defensive

Democratic plans hit from all sides

A1

By J. Jennings Moss
THE WASHINGTON TIMES

The principal Democratic health care reform plans sustained a heavy barrage of artillery yesterday from political factions and special-interest groups.

Democratic leaders, following the lead President Clinton set Wednesday night when he said he is fighting to protect and expand Americans' health insurance, mounted a vigorous defense for some of their main reforms.

House Democrats argued for their plan to expand the federal Medicare program to include up to 50 percent of the public and continued to work on getting 218 Democratic votes for their plan.

Senate Democrats prepared for what is likely to be a long debate on the Senate floor, where conservatives and liberals will try to amend the package to their liking and where no majority is in place to pass anything.

Republicans rallied at Mr. Clinton yesterday for his broadside on the GOP during his prime-time news conference Wednesday.

The president said reporters should shift their questions to congressional Republicans. He noted that several Republicans supported bills that would have required all Americans to have insurance, then backed away from those proposals.

"He wanted to try to mislead people into thinking the only way to solve problems would be some form of Clinton care," said Haley Barbour, chairman of the Republican National Committee.

Republicans in both houses have comprehensive reform proposals built around changing insurance laws and providing subsidies to poor people, although these measures would not achieve universal coverage.

The Senate is set to begin debate Tuesday on a 1,400-page proposal by Majority Leader George Mitchell of Maine. It aims to have 95 percent of the country covered by 2000 and would use employer mandates as a last resort. The debate could take three weeks.

House Majority Leader Richard A. Gephardt of Missouri announced that his timetable for considering legislation has slipped. The House will begin debate Aug. 15 and conclude Aug. 19. Besides proposing to expand Medicare, the House leadership bill would require all businesses to pay 80 percent of their workers' health costs.

"They're starting a serious PR campaign, which will be about their third or fourth serious PR campaign," Mr. Barbour said. "Their problem is not public relations. Their problem is bad public policy."

But the Clinton public relations effort picked up speed.

As part of a $1 million ad campaign the Democratic National Committee is financing, Mr. Clinton began a series of Oval Office messages to be televised every night for at least a week on CNN. CNN agreed to run the ads after ABC, CBS and NBC refused. The campaign also includes radio ads.

Closing out a cross-country bus caravan that was designed to build support for universal coverage but instead drew substantial opposition along the five routes, Vice President Al Gore traveled to Capitol Hill to greet the bus riders in one of many health care events.

Liberal Democratic senators held a news conference to say the Mitchell bill falls far short of their goal of ensuring quick health care for all Americans, and they said their votes on the final bill are guaranteed.

Sen. Russell D. Feingold, Wisconsin Democrat, said he is especially concerned about the willingness of Mr. Clinton and Mr. Mitchell to accept a bill providing 95 percent coverage.

"For me, the mathematics of 95 percent equals 100 percent does not add up," Mr. Feingold said. He said he and other senators will offer amendments to improve coverage and long-term care.

Democratic House leaders spoke to the press about the need for expanded Medicare. Mr. Mitchell's bill does not include such a proposal; it would shift the uninsured and the poor to private coverage.

While Mr. Gephardt was trying to defend a key part of his plan, a lawmaker who usually supports the leadership suggested that the Gephardt plan is a dead issue.

Rep. Patricia Schroeder, Colorado Democrat, said on ABC's "Good Morning America" that she expects Mr. Gephardt's bill to be replaced with Mr. Mitchell's proposal on the House floor.

AP

Al Gore speaks at the last stop of the health reform bus tour.

Moderate Democrats have raised questions about the Gephardt plan and are paying close attention to the work of a bipartisan group of House members. A move such as that suggested by Mrs. Schroeder could draw support to the Democratic leaders' bill and away from the bipartisan approach.

Mr. Gephardt declined to discuss the differences between his and Mr. Mitchell's bills other than to say both measures meet Democrats' goals.

"I have forgotten and given up on trying to game this whole thing," Mr. Gephardt said. "This is a big deal, and it's hard to get these bills together and get them on the floor, and what we can't do is worry about all the process. I can't worry about what George Mitchell is doing."

Republicans kept up a unified assault on both Democratic measures.

"How can you go home as tax king of the universe and expect to be re-elected?" asked House Minority Whip Newt Gingrich of Georgia. Republicans said the Mitchell bill has 17 new taxes.

Many interest groups issued press releases yesterday. Many came from backers of Mr. Clinton's reform efforts and tried to pit Mr. Gephardt's plan against Mr. Mitchell's.

The AFL-CIO and the International Brotherhood of Electrical Workers said the Gephardt proposal is superior. The Council for Affordable Health Insurance praised Mr. Mitchell for dropping "the fixation on 'universal' coverage," although it had other problems with his bill.

HealthRIGHT NEWS

GIVING PEOPLE A VOICE IN THE HEALTH CARE DEBATE

FOR IMMEDIATE RELEASE
FRIDAY, AUGUST 5, 1994

CONTACT: KATHY GARDNER
ROBERTA HAVEL
(202)543-4357

HEALTHRIGHT 'REFORM RIDERS' SPEAK OUT FOR UNIVERSAL HEALTH CARE COVERAGE

A BRIEFING
by
HEALTHRIGHT

AGENDA

10:00 a.m. OPENING REMARKS by the **HONORABLE ARTHUR S. FLEMMING**, Former Secretary, Department of Health, Education, and Welfare, and Chair, HealthRIGHT;

10:05 a.m. **HealthRIGHT** film, "Americans Speak Out on Health Reform"

10:13 a.m. REMARKS by the **HONORABLE MARY ROSE OAKAR**, former Member of the House of Representatives, Member of the U.S. Bipatisan Commission on Health Care Reform, and President of HealthRIGHT;

10:18 a.m. REMARKS by the **HONORABLE SAM GIBBONS,** Acting Chairman, Ways and Means Committee; the **HONORABLE PAT WILLIAMS**, Chairman, House Education and Labor Subcommittee on Labor Management Relations, the **HONORABLE KWEISI MFUME**, Chairman, Congressional Black Caucus; the **HONORABLE BUTLER DERRICK**, Chief Deputy Majority Whip, the **HONORABLE RON WYDEN**, Chairman, Small Business Subcommittee on Regulation, Business Opportunities, and Technology, and other House and Senate leaders;

10:35 a.m. BRIEF REMARKS by **HealthRIGHT 'REFORM RIDERS'**

10:45 a.m. INTRODUCTION OF **FIRST LADY HILLARY RODHAM CLINTON**

10:47 a.m. REMARKS by **FIRST LADY HILLARY RODHAM CLINTON**

HealthRIGHT NEWS

GIVING PEOPLE A VOICE IN THE HEALTH CARE DEBATE

FOR IMMEDIATE RELEASE
AUGUST 3, 1994

CONTACT: KATHY GARDNER or
ROBERTA HAVEL at (202) 543-4357

HEALTHRIGHT CONCLUDES THIRD CROSS-COUNTRY TOUR; VIDEO POLL AND REPORT UNDERSCORE BROAD PUBLIC SUPPORT FOR UNIVERSAL HEALTH CARE COVERAGE

FIRST LADY HILLARY RODHAM CLINTON TO HEAR TESTIMONY OF 'REFORM RIDERS' AT HEALTHRIGHT BRIEFING*

(WASHINGTON, DC) — Dr. Arthur Flemming, former Secretary of Health, Education and Welfare under President Eisenhower and current chairman of **HealthRIGHT**, announced today that he will be releasing the findings of a national video poll and report which underscores broad public support for universal health care coverage. **The report will be released at a press briefing which will be held Friday, August 5, 1994 at 10:00 a.m. in Room 1100 of the Longworth House Office Building.** First Lady Hillary Rodham Clinton will join Acting Ways and Means Chairman Sam Gibbons and other House and Senate leaders at the briefing to hear the testimony of several families videotaped during HealthRIGHT's recent national tour.

"In person and on videotape, **HealthRIGHT "Reform Riders"** and Americans from around the country will urge House and Senate leaders to adopt health reform legislation that will guarantee universal coverage for all Americans. **HealthRIGHT** has videotaped the views of thousands of hard-working Americans from every state in the union over the past three years," Flemming stated. He added, "This unique video petition for health care reform is an unprecedented but highly effective grassroots effort created to inject the concerns of 'real people, not actors' into the current health care debate. In Congress, some legislators have proposed partial solutions which would protect the wealthy and help the poor, while still leaving every middle-class American at risk of losing their insurance. At Friday's briefing, we will hear how without universal coverage, the hard working middle-class American family will not have the peace of mind that this health reform discussion and the resulting legislation should give them."

"If the Congress is truly representative of the will of the people, the future of universal coverage would not be in doubt. In the House, according to our survey, this bill should pass 400 votes to 35. The vast majority of Americans are *on the bus*," said **HealthRIGHT** President Mary Rose Oakar.

A short video featuring views of Americans from each of the 50 states and the District of Columbia will kick off the briefing in which some of the following 'reform riders' will be testifying:

Matt Austin - Billings, MT
Connie Bowen - Portland, OR
Violet Bronson - Yakima, WA
Michelle Brown - Salt Lake City, UT
Larry Clifton - Paradise Valley, AZ
Deborah Dimmick - Grants Pass, OR
Ted and Diane Durbin - Keizer, OR
Marla Fetterhoff - Salem, OR
Jose Gomez Moreno - Wapato, WA
Juanita Long - Salem, OR
Donna Milota and Juliena Milota - Santa Clarita, CA
Anita Monoian - Yakima, WA
Georgia Sandoval - Wapito, WA
John Van Slyke - Eugene, OR
Irma Martin - Olathe, KS
Eugene Sims - Kansas City, MO
B.J. Renfrow - Fairway, KS
DeLana Marie Shipley - Lansing, KS
Richard Ross - Hallsville, TX
Linda Phillips Thune - Austin, TX
Peggy Sackett - Austin, TX
Mary Crain - Austin, TX
Diane Crawford Merrill - Ada, OK
Geneva Howard, Jack C. Howard - Ada, OK
Debbie Clay - Chattanooga, TN
Yvonne Rogers - Metarie, LA
Mitzi Barker - Ooltewah, TN
Helen Vicknair -Kenner, LA
Cecele Centanni - Kenner, LA
Mary Miller - Kenner, LA
Peter and Quincy Sherman - Little Campton, RI
Douglas Eaton - Gorham, ME
Linda Dare - Tigarol, OR
Nancy Denofio - Manchester, NH
Maureen Michael - Manchester, NH
Mildred Hamilton -Chattanooga, TN

* HealthRIGHT completed its third national cross-country tour — in conjunction with Health Security Express — to bring the views and concerns of the American public to elected officials. 'Reform Riders' are those nurses, doctors, working people, retirees, celebrities, and other concerned Americans who traveled on the buses from communities across the United States to bring their message of support for universal coverage to the Congress and the President before the debate on legislative solutions begins.

"The Voices of the People"

The Popular Mandate for Health Care Reform

A Report to the U.S. Congress

HealthRIGHT

August 5, 1994

HealthRIGHT • 505 C Street, NE • Washington, DC 2002 • 202-543-HELP

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I. History and Background

HealthRIGHT was created in January 1992 by a group of former congressional staff members with 50 years of combined experience in health care, all of whom had worked for the late Senator and Representative Claude Pepper. HealthRIGHT was conceived as a mechanism for getting the voice of the American people and their concerns about health care to elected officials in the executive and legislative branches of the federal government. HealthRIGHT's initial goal was to continue the work of Pepper, who was preeminent in his care and concern for the problems of the American public. Pepper was well known for traveling to every corner of America, conducting rallies and hearings, and listening to the public and thereafter presenting reports.

HealthRIGHT's first national tour was conducted in summer 1992. HealthRIGHT cameras traveled to 10 states, covering 8,000 miles and both the Republican and Democratic National Conventions.

In January 1993 HealthRIGHT presented the findings of the tour in its first report to the Congress at hearings of the House Select Committee on Aging. A second event, held in the House of Representatives in March, included the presentation of statements from citizens presented live and via videotape. To validate its findings, HealthRIGHT also commissioned and presented the results of national opinion surveys by Louis Harris and Associates and The Gallup Organization.

On the basis of the successful reception HealthRIGHT enjoyed in local communities and before Congress, it expanded its petitioning efforts to the national level. In 1993 HealthRIGHT conducted its first major tour, called "Speak Out, America!" This 16,000-mile odyssey into all 50 states and the District of Columbia began in June and was completed in September.

In the last three months of 1993 HealthRIGHT produced a series of television commercials featuring individuals who had come forward to give their views about health care. A national television advertising campaign was launched in January to some 40 media markets; subsequent, indepth coverage appeared in Washington, DC.

In January 1994 HealthRIGHT held another major congressional hearings, again bringing representatives from all 50 states and the District of Columbia to tell their stories to the Senate leadership. Senator George Mitchell, Senator Tom Daschle, and Senator David Pryor, who all participated in this event, called it one of the most positive and extraordinary hearings in which they have participated in their many years in Washington.

In March 1994 HealthRIGHT conducted another hearing, together with the leadership of the House of Representatives. This event focused on the special health care problems of the elderly. First Lady Hillary Rodham Clinton participated in this event.

In May 1994 yet another hearing was scheduled with the Senate leadership, highlighting the special health care problems of children. The First Lady participated in this hearing, as well, which—as did all that preceded it—obtained widespread publicity. In June another hearing was held on the health care needs of working, middle class Americans, both House and Senate leadership participated.

HealthRIGHT began another tour in June 1994, visiting 26 states in America's heartland. HealthRIGHT traveled more than 11,000 miles, stopping in more than 40 major cities to collect

and record the views of the American public. On July 20 the Democratic leadership heard the findings from the Heartland Tour.

In addition to all of the above, HealthRIGHT has produced one full-hour and three half-hour documentary films that highlight real health care problems of real people. These programs have been aired on national television.

To date, HealthRIGHT has traveled more than 45,000 miles, the equivalent of circumnavigating the world twice and crossing the United States 15 times.

Beginning on July 22 HealthRIGHT became one of three major sponsors of the Health Security Express, a caravan of buses traveling from every corner of the United States and converging on Washington, DC. on August 3 and 4. These buses traveled an additional 10,000 miles; at every step along the way, HealthRIGHT cameras recorded the voices and opinions of the American people. The final written report from the Express tour, together with a video petition featuring all of the American people who talked to HealthRIGHT, was presented to the Congress and the President of the United States in the form of a video wall.

II. The Process

HealthRIGHT began as the first-ever electronic video petition to the government. Traditionally, Americans have written letters or marched, but future generations will use the computer and the mechanism of videotape to bring their messages forward to the government. Because HealthRIGHT was the first such electronic petition, it has received an inordinate amount of coverage in the public press.

As originally conceived, the television camera was substituted for Pepper. The public was invited to state its views without any prompting and without any preconceived agenda, as if individuals were speaking to Pepper. They were free to say anything they wanted to say, and these views in their entirety were captured on videotape.

In addition to providing people with informal opportunities to express their views at shopping malls, senior citizen centers, and other places where people congregate, HealthRIGHT held a number of formal hearings, moderated by its Chair, the Honorable Arthur Flemming, its president, former Representative Mary Rose Oakar, or another of its founding board members, former Senator Frank E. Moss.

HealthRIGHT also took its television cameras into private homes on home care visits to solicit the views of homebound or disabled individuals.

As noted above, HealthRIGHT commissioned opinion surveys by the Harris and Gallup organization. HealthRIGHT also sent out its own surveys and did its share of opinion research.

The intent from the beginning was to weave a giant net that pulled together the views of the American public with respect to health care reform. The intent was to empower the American people and to help their concerns and their very real needs remain the focus of health care reform, rather than institutional or other special interest groups.

HealthRIGHT has thought of itself as the people's lobby and will continue to play this role until health care reform is enacted into law.

III. The Evidence

In all the tours and meetings HealthRIGHT has held across the country and on Capitol Hill, Americans who need health care told the cameras that they are in trouble. Even those who most people think are covered—working Americans, relatively wealthy Americans, or those close to the poverty line—find that the safety net they thought was there does not exist. What follows are the voices of people across this country about the very real problems they have faced, challenges they have tried to overcome, and obstacles they have come up against in getting the care they need, when they need it, in the setting they prefer most.

- Solon Blundell, 72, of Huntsville, Alabama, and his wife, have been caregivers for 25 years. Some of that time was spent caring for his mother-in-law, who lived to be 98 years old and suffered a series of strokes that left her paralyzed. Some of this time was spent caring for their 45-year-old daughter, Becky, who was diagnosed with Lou Gehrig's disease in 1986 and is now bedbound and ventilator dependent. For part of those 25 years the Blundells were taking care of the younger and older generation in their home at the same time. "I had to stay in the workforce four years more than I intended to help pay my family's medical bills," said Blundell. "We have been borrowing against our home equity to pay for medical bills. It's going fast. Once the money is gone, we don't know what we will do. Please include long-term care in health care reform."

- Sue White of Fairbanks, Alaska, is the adoptive mother of six children, all of whom have medical conditions that require special consideration. Devon, her 10-year-old son, suffers from Weidemann's syndrome, which is a dwarfing disorder. He also has attention deficit disorder, is recovering from malnutrition, rickets, and scurvy, and is learning disabled. Sue White found that the options available for meeting her children's health care needs were extremely limited. Four years ago, White was diagnosed with cancer, and her options became even fewer. She said, "We were advised that we could do a number of things. We could divorce. My husband and I had been married for 24 years, and we felt that wasn't an option. We could impoverish ourselves, which we really did not want to do. We could turn our children back to the state. Or, if I decided not to pursue my own treatment, my husband could receive benefits for the children after I died." None of these options were acceptable, but now White may have to face these impossible choices: her husband's company is downsizing, and with the preexisting conditions in her family, she's convinced that they'll be uninsurable if he loses his job.

- When Stephanie Boone, 14, of Phoenix, Arizona, was nine months old, she was diagnosed with a malignant brain tumor. Because her father works for the state, the family has good insurance coverage, but the 20% copayment (uncovered out-of-pocket costs) have accumulated to the point where the family is near bankruptcy. "Even with insurance you can go bankrupt," Stephanie's mother said. "We had to put a second mortgage on our home that we are still paying off 13 years later." Stephanie is going without many needed services. For example, she needs many medications that are not paid for, and her daily physical therapy sessions are cut back, even though she needs physical therapy to maintain her muscle tone. Her father does not dare to leave his state job for fear that Stephanie's preexisting conditions will not be covered by another employer. The family lives in dread of the day that she turns 18, because as an adult she will no longer be covered on the family health insurance policy. "What

happened in the past was terrible and terrifying, but we got through it," said Boone. "But what about the future? We just don't know how to plan for it."

- Spenser Villinger, 2, of Little Rock, Arkansas, experienced respiratory distress for the first two years of his life, and as a result requires mechanical assistance to breathe efficiently. He was hospitalized continuously for the first nine months of his life, which resulted in his reaching the lifetime limit of $1 million insurance policy. Spencer is ventilator dependent and requires continuous home nursing and physical, occupational, and respiratory therapy services. He receives only a small part of what he needs because of constraints in the state's Medicaid program. The family has endured financial and emotional hardships as they have struggled to meet their son's many needs and want to do everything possible to ensure that he receives comprehensive home care services. His mother says, "He deserves access to some opportunities that [other] children have. Please allow access to funding so that all children, regardless of financial status, may have these opportunities. Let health care reform be designed to keep the families of the United States together."

- Kay Knapp, 83, of Sacramento, California, has congestive heart failure and recently had hip replacement surgery. A retired nurse, Knapp came through the hip surgery well but contracted flu while receiving rehabilitation therapy afterwards. The flu took away her appetite and she lost 17 pounds. Her doctors sent her to a convalescent home for two weeks to get her strength back. Discharged, she was home for one hour before suffering a heart attack. Knapp spent eight weeks in the hospital this time but got the word from Medicare and Aetna that she'd exhausted her hospital benefits after 16 days. She is staying with her two sons for the time being, because she is not well enough to take care of herself. Knapp said, "My options were to spend $3,200 for a nursing home or $1,400 for assisted living in a retirement home, either one a huge sum on $700 a month income." Knapp strongly believes that, "whether you are Republican or Democrat, the priority is the needs of the American people. So, let's get with it."

- At 15 months of age, Brian Smith, 12, of Commerce City, Colorado, choked on a corn chip that obstructed his airway. The result was severe brain damage. He is in a persistent vegetative state, and depends on others for 24-hour care. He has a tracheostomy (an incision in his windpipe with an artificial tube to breathe). He is fed with a second tube inserted straight into his stomach. He requires home nursing care and aide services, as well as 24-hour-a-day rehabilitative therapy, which his family provides. Their care is augmented by limited services provided by the state Medicaid program. The family fears he will soon lose coverage under Medicaid. Nancy Smith, Brian's mother, explains, "Imagine, as a parent, making decisions that could destroy your whole family. This is our situation come August: our eldest son will graduate from high school and will be turning 18, so the situation we face is that Brian will then be cut off from Medicaid because our income is too high." They have been told that their only recourse is to give up their child to the state or to obtain a divorce and thus be eligible for Medicaid. "We will be bankrupt in a very short time if we lose Medicaid," Smith continues. "Brian's medical bills are three times what my husband makes. The worst nightmare that a parent can face is having a special needs child, but something even worse is having to fight for these kids forever. You're trying to keep your family together and they're forcing you apart."

- Arabella Piña, 61, of West Haven, Connecticut, was first treated by a hospice last June for breast cancer, which was diagnosed in 1987. Fortunately, she's outlived her doctor's

prediction that she had six months to live. Now she has cancer of the brain. She is on a lot of medication and in a lot of pain. "God is not finished with me yet," she said. "When the third cancer hit me last year, I gave up. I said, 'Not again. I can't take it anymore.'" She is able to get some assistance in the home from hospice. This is crucial, she says, because she does live alone and wants to remain independent for as long as possible. "Thank God for hospice and home care," Piña says. "They have given me such support. I have courage now to live and I'm on my way to recovery, and I don't have to worry about going in the hospital again. I have home care. I ask you to keep home care in your package. We need it, all men and women."

- Elizabeth Logue, 8, of Wilmington, Delaware, was born with a congenital heart problem. Surgery successfully repaired her heart, but problems with the anesthesia left her with severe brain damage. She needs 24-hour home nursing care and other assistance to remain at home. The costs are enormous—more than $200,000 a year. Although their insurance and the state of Delaware have provided a hedge against bankruptcy, the family lives in fear that Elizabeth's father may lose his job because of continual layoffs, leaving the family without protection because of their daughter's preexisting condition. "My insurance," explains Elizabeth's father, Michael, "has been excellent thus far. I worry that it is not going to be there in the future. Large corporations are downsizing, and special needs children cost a lot of money. I have heard many people talk about programs, but a lot of these programs don't take into consideration the personal costs and anguish that we go through, not only the emotional and physical distress with the handicapped child, but trying to do for the other children of the family." The Logues would like to see portable insurance, so that working parents can change jobs. "The rising cost of insurance premiums are going higher than the federal deficit. We need control and we need change now." Logues stresses. "United, we can do it. Let's get it done."

- Candida Di Croce, of Washington, DC, lost her husband to Alzheimer's disease in 1992. She was the primary caregiver for her husband, and as his illness progressed, he was confined to his home. She relied on a neighbor to help with his care while she continued her government job to support them. "During the 10 years of his illness, the expenses were exorbitant," she says, having spent $21,000 a year in out-of-pocket expenses. "I lived with the concern that we could end up on Welfare, a thought that was devastating and appalling because together we had worked 100 years." More than a year after his death, she was still dealing with massive paperwork and health care bills. " I am committed to the cause of long-term care so that others can be spared the suffering that catastrophic illnesses bring to families. I hope and pray that the new reform bill will alleviate the burden of all people in need." She concludes, "Too many people are not covered. All of us should have adequate health coverage. If we have our health, we can do almost anything."

- Frances Hightower, of Tallahassee, Florida, has mortgaged three family homes and exhausted all the family savings in her efforts to pay for her relatives' care. She works for the state of Florida full time and is also the full-time primary caregiver for her family. Her mother, who died of Alzheimer's on January 3, 1994, required 24-hour custodial care for her last seven years, which was not covered by the state health insurance. She did not qualify for Medicaid because her retirement income exceeded $1,302 a month. Hightower's older brother lives at home. He's 63 years old and retarded, diabetic, and disabled, and he also requires 24-hour care. Her father, 88 years old, lives at home with her brother and has needed help taking care of

himself since he suffered a heart attack. Three years ago Hightower mortgaged her house, her parents' house, and her younger brother's house to meet the expenses that insurance and the health care system will not cover. In January 1994 she refinanced all three mortgages in the hope that she can continue to care for her family at home. "The lack of long-term care and home health care is emotionally and financially devastating," she says. "I'm frightened about the prospect of what is going to happen to millions of Americans when they get in this shape—and to people like me who are trying to take care of them. We've got to find a way to provide for people when they are old or when they are ill; when they can't take care of themselves; and when the insurance they've had all their lives does not provide the kind of care they need."

- For the last 10 years, Mildred Hill, of Savannah, Georgia, her husband, and her daughter Kirsten have been the caregivers of her parents and a cousin. Her father had Paget's disease, heart disease, and dementia from stroke; he died at home in his sleep last November. Her mother has Alzheimer's disease; the cousin is in the early stages of Alzheimer's. Mrs. Hill works long hours, often at night, as a restaurant owner, leaving Kirsten to care for the older relatives. Kirsten has been helping her mother since she was 10 or 11 years old. She lost much of her childhood because she had to grow up quickly to take on this responsibility. Speaking with an adult perspective, she says, "If home health care was more affordable, this would not have happened." Mrs. Hill says, "What worries me is that we are middle-class Americans, and my father made the mistake of working a little bit too hard. If [my mother] had to enter a nursing home in a private-pay institution, it would be a tremendous drain."

- Three years ago, Sterling Krysler, 40, of Honolulu, Hawaii, was injured in a surfing accident that rendered him a quadriplegic. "Prior to that accident, the thought of being disabled never occurred to me," he said. "Things like that only happened to other people." Thanks to Medicaid's Nursing Home Without Walls program in Honolulu, Hawaii, Krysler can stay at home. "Fortunately for me, my family chose to care for me at home despite all the obstacles. The families that choose to care for their loved ones at home have a strength of spirit and character that is unsurpassed. It goes to the moral fabric of this country." Not only does the program save the state thousands of dollars, but it allows Krysler to stay in the comfort of his own home. The services he receives include respite care for his wife and children. "I would implore you to help those families who choose to care for their loved ones at home, especially the children," he concludes.

- John Hoggan, of Idaho Falls, Idaho, talked about his first wife and the mother of his six children, who in 1983 was diagnosed with cardiomyopathy, a rare heart disease. She died a year later. In 1992 Hoggan's youngest daughter, Chantel, was also diagnosed with cardiomyopathy. Hoggan's insurance premiums had skyrocketed and he had been forced to drop his coverage. In 1992 he tried to purchase new insurance, but no one would insure him at any cost because of Chantel's preexisting condition. He tried to apply for public assistance but was turned down because, at $20,000 a year, he made too much money. Hoggan was able to get Chantel on Supplementary Security Income, which made her eligible for Medicaid and enabled her to receive the much-needed heart transplant in November 1993. Hoggan is caught in a bind: if he makes more than $24,000 a year, his daughter will lose the Medicaid benefits. There is no way that he could pay for the $40,000 in hospital visits or medications that she requires to stay alive. "We have seen our health insurance premiums double, triple and become totally

unaffordable," Hoggan states. "We have been forced to plead and beg state, county, and federal agencies for help. We have been turned down for new health insurance due to preexisting conditions. We have been forced into bankruptcy due in part to medical bills. There may not be a health care crisis in your world, but there is in mine." He continues, "Our world is tough enough when tragedy strikes, without being torn apart by the thought that financial ruin lies just ahead. This great country is the keeper and provider for the world. Isn't it time that we care and provide for the elderly and the sick children of this country?"

- Dr. Tom Levin of Chicago, Illinois, is a cardiologist at the University of Chicago Hospitals. He is concerned about the quality of care his patients receive as a result of the restrictions placed on medicine by insurance companies, indicating that physicians no longer have the freedom and responsibility to practice medicine as they see fit—without looking over their shoulders to see what is and is not covered. "As a health care provider, I am becoming more and more frustrated each day with insurance companies, health maintenance organizations, and cost-conscious managed care agencies that are trying to influence the way we practice medicine. In this country's affluent society, we have the ability to provide very high-quality care, very state-of-the-art care, and sometimes I feel as if I'm being asked to jeopardize the quality of the care I deliver to keep costs down. That's inappropriate." He believes that it is the patient who suffers when insurance companies—rather than doctors—make medical decisions. Each patient, he feels should receive the treatment he or she deserves, and not what is "proper" procedure according to some regulation.

- Marie Hower, 62, of Decatur, Indiana, suffered a massive stroke in 1989 and was left paralyzed on her left side. "It took me a long time to learn to talk and walk all over again, like a baby, " she told us. "It's so very hard." She doesn't qualify for total disability but receives about $250 a month from Social Security and disability combined. Her husband had a stroke and went on total disability in 1973. He also has high blood pressure and other problems. They receive a limited amount of home care but need more. Mrs. Hower's twin sister, Mary Dutton of New Haven, went into a coma unexpectedly several years ago but was too young for Medicare and was left with $19,000 in hospital bills. Both sisters were able to travel to Washington, DC, to tell legislators about their problems. Dutton summarized her sister's need for home care: "Without home care, Marie wouldn't be able to exist at home. She would have to be in a nursing home. Her husband would have to be in a nursing home, and I think they would just shrivel up and die. They are very independent, headstrong, and they love life." Marie is one of hundreds of thousands of elderly and afflicted citizens around the country who need assisted services. Assisted service is essential, intermediate care, day care, adult day care, Alzheimer's care, and a host of other community-based services that deal with a myriad of problems that Marie and some of the others have to deal with every day. As Marie and her sister exemplify, assisted services are essential; the sisters strongly hope it is included in reform.

- Erma Zimmerman, from Sioux City, Iowa, is married to Gary, who was stricken with Alzheimer's disease in 1980 at the age of 50. The disease quickly impaired Gary's ability to earn a living as a skilled carpenter, and because he couldn't work, the couple had no medical coverage. All their financial resources have been completely exhausted, and she is left with major debts. Zimmerman tried to care for her husband at home, although he could not be left alone. It was "the most stressful caregiving imaginable," she says. "During my daily hours of

employment, his aging parents filled in as caregivers. This responsibility eventually took its toll, contributing to his mother's premature death." With no outside help for caregiving, Zimmerman eventually had to let her husband go to a nursing home. Zimmerman says, "Very little can be done for my Gary at this time, but hopefully my sharing here will help you make a difference for those who come after us."

- Winnie Hesse, 48, from Topeka, Kansas, is waiting for a heart transplant. Only 13% of her heart is functioning, as a result of a viral infection. The family's insurance does not cover the costs of transplants, so the Hesses looked elsewhere for help. "The first two hospitals that we asked said, 'Thanks for coming and please leave.' The third hospital that we went to said, 'We'll talk to you with a $50,000 deposit.'" The Hesses raised more than $150,000 for the operation and her first year of care through community car washes, garage sales, and strudel sales. Winnie is now 11th on a list for a heart transplant. If the transplant is successful, maintenance medications will cost between $10,000 and $20,000 a year for the rest of her life. She explained, "I now have a preexisting condition that will never be covered again. ... I don't know what I'm going to do. There are a lot of Hesse families out there that don't want their loved ones not to get the care they need because resources aren't there."

- Willie Garr, from Lexington, Kentucky, found herself falling between the health care cracks when she needed bypass surgery. She had high medical bills because of the procedure, but she wasn't working, didn't qualify for Medicaid, and wasn't old enough to qualify for Medicare. "Out of my $600-a-month Social Security check, I'm now spending about $300 a month for medical expenses and supplementary insurance. [This situation] taught me that I would have to buy supplementary insurance, whether I could afford it or not, which means I have to do without something else." Garr has to "budget real close" to make ends meet. "I am very concerned about the fact that a lot of senior citizens, believe it or not, have to make a decision every month: 'Am I going to buy medication or am I going to buy food?'"

- Ann Reiley Jones of Baton Rouge, Louisiana, is Special Assistant to Governor Edwin Edwards for Health Care and Hospitals, and also serves as Chairman of the Louisiana Health Care Commission for Commissioner of Insurance Jim Brown. Her state is the only state in the nation that has a statewide charity hospital system. "It is indeed a unique and distinguished delivery system, unlike any other in the United States. Since 1736 the state of Louisiana has furnished universal access to the disadvantaged, underprivileged, poor, and unfortunate. This is a system that should be duplicated because it has worked very well." Jones is also concerned about access to health care in rural areas. "Vast areas of our country—64% of the area in Louisiana—are rural or underserved" and suffer a shortage of providers, she states. She encouraged innovative solutions such as salary supplements or telemedicine and long-distance learning, to bring technology to the underserved and rural areas of the nation. To reform the system, Jones feels, legislators must involve physicians and nurses, who are the implementors and deliverers of health care. "They must be involved at the very beginning of the process and through to the end," she said.

- Rose Rogan-Dinsmore, 66, of Dexter, Maine, suffered a head injury at age 61 and, as a result, lost her job and her health insurance. Rogan-Dinsmore was unable to secure another job, so for five years she got by without health coverage, being too young to qualify for Medicare. She borrowed from family members when health bills came due and paid for her prescription

drugs with credit cards. At the same time, she and her husband cared for his parents, who were in their 80s and had no resources but needed around-the-clock assistance. "It was a nightmare," she said. "I don't want to be treated like a second-class citizen when I ask for help." She told legislators, "I think the worst thing about it, that I wish Congress would understand is, I really don't want your money. I want you to give us back our self-respect. Please, give us affordable, universal health care and give us back our dignity. The spirit of America will be broken if you don't do that."

- Michele Peterson and her son Michael hail from Potomac, Maryland. Michael has aplastic anemia, a rare blood disease that required a bone marrow transplant to save his life. The costs of his care have exceeded $800,000; the family's insurance would not pay for more than $250,000. "We thought we were safe; we had insurance," Mrs. Peterson said. Community fundraising efforts have thus far raised about $60,000 toward the bill. Yet even with community fundraising efforts, this type of medical expense will bankrupt any middle-class family. "It is a shame that in this country a young boy should have to become a focus of the media to raise money to pay for his health care," his mother stated. "I believe that America can and should support a comprehensive health care system that all Americans will have access to long-term care, without being denied insurance because of a preexisting condition."

- Daniel Cresek, 7, of Ipswich, Massachusetts, was just one week old when he went into cardiac arrest. He was diagnosed with aortic atresia and VSD, a rare defect, and needed open heart surgery several times before his first birthday. The family thought it was protected by insurance, but when Daniel was six months old the insurance company informed the family that the insurance premium would increase from $198 a month to $766 a month. Daniel's mother called the insurance company, thinking they had made an error. "I was told they are not in the business of paying our medical bills, they were only there to defer the costs." Thirteen months later, the insurance premium went up to $1,375 a month. The Creseks, who own a small restaurant, tried to find less expensive insurance to cover Daniel as well as the restaurant's employees. They were turned down because of Daniel's preexisting condition and continuing excessive medical costs. Eventually they were forced to drop their son from their insurance coverage so that they could continue to cover their restaurant employees, which they feel strongly about. The family wrote to the Insurance Commissioner's office and asked whether the insurance companies could do this. The reply: the insurance companies were fully justified. The insurance company informed the Greseks that if they did not like what it was doing, they could discontinue participation in their group and purchase insurance from another carrier. "They were laughing at us and knew, as we did, that with Daniel's preexisting condition, no other company would insure us," Mrs. Gresek says. The Greseks ended up paying more than $23,000 in out-of-pocket expenses for Daniel's care; eventually they were forced to sell their home. They could not afford the medical costs: the bills for the first three months were more than $150,000; for the first two years, the total was more than $300,00. Daniel is now covered by a state Medicaid plan. The Greseks are still worried, however; the current governor of Massachusetts wants to repeal what he calls "the entitlement act" that affords Daniel his care. Mrs. Gresek is understandably distressed. "My husband and I have always paid for insurance, since we were 18 years old and off of our parents' policy. But when we needed them the most, they left us high and dry." She is convinced that the insurance system must be revamped under health care reform. "It seems to me that the only thing that the private insurance companies insure these

days is their profits. Access to health care is not a luxury, it is a necessity and I think we should protect our children's quality of life."

- Siegfried Hoffman of Grosse Pointe Woods, Michigan, was training for the Detroit Free Press marathon in Grosse Pointe, Michigan, when he noticed a twitch in his arm. It was the first signal of Lou Gehrig's disease, a degenerative disease that normally kills patients within three to five years after diagnosis. Hoffman, who still works, had never filed a claim with his insurance company before the diagnosis. He said, "When I needed my health care after 28 years of perfect attendance at my job, I had to hire a lawyer to get my health insurance company to pay for my treatment.... If you have to fight the disease and the insurance company and the hospital just to get someone to take care of you, that is pretty tough psychologically."

- For Monta Childers, 80, of St. Paul, Minnesota, the health care nightmare began September 9, 1990, when her husband underwent a quadruple bypass operation. When he came home from the hospital, the money the couple had saved for glasses, hearing aids, and getting their teeth fixed went for a new furnace. Their total annual income at that time was some $10,000—but their bills were more than $16,000. Their bills for Mr. Childers's medications alone were $721 a month, none of it covered by Medicare or any insurance. Her husband has since died, and Mrs. Childers is still left with many unpaid medical bills. The paperwork—at last count 95 bills—was impossible for her to comprehend. Childers herself suffers from arthritis and an enlarged heart and must pay for her medications as well. She had to cut out two prescriptions. She said, "They were just getting a little bit too doggone expensive. All of my life there wasn't much I couldn't do. But I can't do any of that stuff anymore. If I didn't have my crazy sense of humor, I would be climbing the walls." Despite her sense of humor, she understandably wants to see a streamlining of the health care billing process.

- A home health nurse from rural Vicksburg, Mississippi, Mary Jourdan spoke to us on behalf of her patients. Many of them live in terrible poverty, with no electricity, no running water, no transportation available to get to a doctor. "These patients consider health care a luxury," she explained. "It shouldn't be that way. Health care should be a right; it should be available to all people." With a degree in community health nursing, Jourdan thinks that with any health care reform, "We need to think of prevention as being a core part of that reform. Nurses can take a big part in health care, more than we are doing now, particularly in the role of prevention and service to the poor in so many underserved areas in our country."

- Dolishia Rankin, 13, from Kansas City, Missouri, has suffered from diabetes, kidney problems and severe depression for more than a year. At times she is suicidal. For the past three years she has required multiple hospitalizations. Her mother works full time driving a school bus, but her mother's employer does not provide health insurance. Over this period her family has repeatedly tried to obtain financial assistance from Medicaid for Dolishia. At one point, the family's income was just $12 a month in excess of the eligibility limit. Dolishia's mother, Jamesetta Williams, explained, "I am what is called the working poor. I am a part-time permanent worker. I have no medical coverage, and I cannot afford coverage on my salary." After multiple efforts they ultimately qualified for Supplemental Security Income, which now allows them to receive Medicaid. "It is hard to see a child that you love have to suffer without the right medication and hospitalization, because you don't qualify. We need medical coverage for all people in this country," says Williams, "and we need it bad."

• Helyn Neiss, 73, of Billings, Montana, is diabetic, has suffered four strokes in recent years, and has had glaucoma for more than 30 years. She lives by herself, unable to afford the home care she requires. She had cataract surgery and lost the sight in one eye completely. She had surgery on the other eye last year and is able to see some in that eye. She cannot read. Neiss has received some home care from the time she was in the hospital. Her main worry was taking her insulin, which needs to be measured out very carefully. To attempt to fill the gap, her daughter prepares syringes for her to last for extended periods of time and prepackages food to last for weeks at a time. The uncovered costs of her medications alone eat up about 80% of her Social Security income. She said, "My main concern is you never know what is up ahead. You just don't know what can happen to you." She urged the people of the United States to "go for home health care and old age help. Let's not fight the President. Let's cease the bickering."

• A health care provider himself, Dennis Mundorf from Lincoln, Nebraska, has his own problems with the country's current health care system. Mundorf teaches aerobics, does not smoke, eats right, and is obviously healthy, yet he cannot get health insurance: he is HIV positive and has been for nearly 10 years. "I work very hard to pay my taxes annually. I pay a third of my income out in federal and Social Security tax. However, every day all I can think about is what's going to happen when I can no longer afford to pay just to see my doctor?" he said. Mundorf feels he has only one choice: to go with the system now, which means he would have to go into the hospital next time he gets sick, quit his job, file for bankruptcy, and apply for disability or go on welfare to get health care. "I think that's a tragedy," continued Mundorf, "because in these United States, being a proud American, I feel we can afford to help out the entire world." Mundorf feels that today he would rather walk outside and get hit by a truck and be killed instantly than face the health care system as it is today. "The thing that frightens me most is we're all wrapped up in dollars. Health care isn't about dollars and cents; it's about people. That's what this country is about."

• Erin Dowell, 27, of Reno, Nevada, was diagnosed with acute myelogenous leukemia in August 1992. Since then she has undergone six chemotherapy treatments, one failed bone marrow transplant that cost—for 52 days of hospitalization—close to $400,000. A second bone marrow transplant will cost an additional half million dollars. "I have no insurance," Dowell explained. "Medicare, which pays 80%, pays me $600 a month, but that's too much money for me to get Medicaid. People in my position need to put our energy into getting well and to surviving this instead of fighting with bill collectors and people that call and make more stress. We've got enough to worry about. We should just be able to get well."

• In June of 1989, Matthew McKenzie, 16, of Manchester, New Hampshire received a lifesaving liver transplant after years of managing a progressive liver disease. As the son of a city firefighter and a registered nurse, Matthew is covered by one of the most comprehensive medical insurance policies that is currently available. Today, Matthew is a strong and healthy honor student involved in sports at local Manchester Central High School. His parents have tried their best to prepare Matthew and provide for him during his first 16 years. But their stewardship will soon end and Matthew will take his place among those adults in the society who will carry with them a preexisting medical condition. His father, Mark McKenzie, said, "We have coped with his illness and we have coped with the issue of portability in the job, in the workplace, and now it is up to this Senate and this House to work on reforms in the medical

system that will provide Matthew with the kind of care that he needs in the months and the years ahead."

- Annie Rose Johnston, 82, of Newark, New Jersey, although blind since infancy, worked 32 years and raised two children. An accident at work in 1985 pulled a muscle and broke a bone, leaving her disabled. She also had blood clots and spent an extended time in the hospital in 1993. She explained, "When I came home from the hospital, the doctor gave me a prescription. I asked how much, and she said, $214. I think my head hit the ceiling. I didn't have 14 cents at the time." Johnston has Medicare and Blue Cross, plus a supplemental policy that costs $112.75 a month. Despite this coverage, she gets no help with her medications. She sells a line of spices and liniments to help her pay for her care. "I get by and that's about it," she said. She stresses that seniors—and some who are not senior—are in need of long-term health care. "We need the medical card. If you make $16,171, you are entitled to the medical prescription card for prescription drugs. But if you make a penny over, you are not entitled to that card." Speaking directly to lawmakers, Johnston concluded, "Please pass the bill to extend long-term health care."

- Shane Benally, 8, of Shiprock, New Mexico, was born four weeks premature. At four months of age, he got pneumonia, which turned into a viral infection in his lungs. The result was broncho-pulmonary dysplasia, a respiratory disorder that required him to be on a ventilator for the first year of his life. Now he has a tracheostomy, a surgical incision in his windpipe to help him to breathe, and is fed by means of a gastrostomy tube inserted down his esophagus and directly into his stomach. He has a seizure disorder requiring medical supervision. The Benallys receive the services of a licensed practical nurse 35 hours a week through the state's Medicaid waiver program. However, in this rural part of the Navajo Reservation, when Shane's nurse is sick or unavailable, no one is available to substitute for her. Shane's mother provides considerable care, but she is in danger of losing her job as a church secretary because of her frequent absences. "Health care reform should be for everybody," she said. "People in rural areas have the same needs as other people, and young people's health problems are just as serious as older people's."

- Kallie Jones, 3, of Conkland, New York, was born with Down's syndrome, suffered from asthma, epilepsy, a heart defect, and a swallowing disorder. She required 24-hour care. She needed chest massage and respiratory therapy four times a day. She was on seizure medication. Kallie had been hospitalized three times and had two major surgeries out of town, and a dozen or so outpatient procedures. Her mother, Rene Jones, said, "The financial and physical burden on my husband and myself was overwhelming. The emotional stress of loving and caring for a sick child affected all of us deeply, including Kallie's two brothers, Ryan and Daniel." In October 1991 they applied for a home care Medicaid waiver program in New York. "Let me tell you how our lives have changed in the last two years," said Mrs. Jones. "Since this service started, Kallie has not had one overnight hospital stay. She was retaught to swallow and chew properly. She was completely rehabilitated and her feeding tube was removed. Kallie has learned to crawl and to walk. This program gave us our lives back."

- Joel Tetterton, 1, of Newport, North Carolina, has already undergone a heart transplant. At two months of age he was diagnosed with Kawasaki's disease, a rare condition the most serious complication of which is the ballooning of the arteries supplying blood to the heart. A

heart transplant was required to save his life. The Tettertons were fortunate to have a health insurance policy. In the year since that procedure, Joel has used about $800,000 of his lifetime cap of $1 million. Because Mr. Tetterton, who is self-employed, was unable to work much last year, Joel qualified for Medicaid, which pays for his prescription drugs. But if Mr. Tetterton has a good year of work, they will lose Medicaid coverage for many of Joel's expenses and will chip away at the remaining amount of insurance available. "I wonder if you're better off not working," said Joel's mother. "Not to have a salary is one way of getting good medical coverage. It doesn't make sense."

- Georgia Coyle, 76, of Fargo, North Dakota, has had Parkinson's disease for 14 years. Her son died from AIDS several years ago. He was not covered under any insurance program, so the family provided around-the-clock care. Her late husband, whom she tried to care for as long as possible, had heart disease for 11 years. After his death, Coyle moved in with her daughter but soon she needed more care than her daughter could give. She has recently entered a retirement community which meets all her medical needs but is expensive and, in addition, Coyle's medications cost about $1,000 a month. She has learned how devastating it is to be faced with exorbitant costs for prescription drugs and nursing home costs. Her suggestion for reform is to cut down on the paperwork required—for nursing homes and hospitals, "so that the staff can spend more time with the patients rather than their pens."

- Five years ago Rose Ann Kinser of Cleveland, Ohio, was diagnosed with alpha I/ambitriptin deficiency—a form of emphysema. She requires IV infusions four times a week, which costs $2,300. Without this treatment she would die. Because of her disease, she has lost her job and her health insurance. She fought for Medicare assistance but was consistently denied for two years. To receive medical care, she had to file bankruptcy and be placed on Medicaid. Kinser has worked hard her whole life. She had good insurance, always paid her bills on time. But playing by the rules didn't help Kinser, because at a time when she desperately needed help, there was none. "What do people like me do?" she asked. "I only hope that no one else will have to go through the degrading, begging process I went through in order to live."

- Jean Benson, of Oklahoma City, Oklahoma, represents the sandwich generation. She told us, "When my father died last spring, I was forced to quit my job and move from Florida to take care of my mother, who has Alzheimer's disease. In the six weeks following my father's death, my mother was overmedicated and neglected, and the situation was so severe that I felt I had to go take care of her before the nursing home did her in." Benson asked for a leave of absence from her employer, but it was denied, so she and her 17-year-old son moved to Oklahoma City. Benson continued her insurance coverage through COBRA: she had no money coming in and the insurance cost $260 a month, but she was afraid to go without coverage. "Good care is almost impossible to find in a nursing home," she explained. "They're understaffed, they're dehumanizing, and they're dangerous. In addition, the regulatory agencies don't do their job in ensuring a safe environment. We must include long-term care in the health plan, and we must ensure that we have adequate standards of care for the people who live there."

- John Van Slyke, of Eugene, Oregon, has a small restaurant with 17 employees. He has been unable to insure them because several of them have preexisting health conditions. "The problem is one of cost control, having the insurance be affordable, and having it available to all

my employees, regardless of their preexisting health conditions," said Van Slyke. One of his employees developed cervical cancer last year and ended up going to Thailand, her home country, where they do have national health care. She was treated very well, came back, and is healed. "I think it's unfortunate that a country like the United States can't compete in delivering health care as well as Thailand," Van Slyke said. "I know I'm going to have to pay more to do it, and I'm absolutely willing to do that if the plan does the job it's supposed to do: provides good preventive health care and covers everybody."

- Dr. Alice Trisdorfer, of Philadelphia, Pennsylvania, is a psychologist at Children's Hospital, Philadelphia. Her patients include children with mental health as well as surgical care needs. These children usually get medically necessary surgery but are often left without the special cognitive and emotional services they require to be active members of society. This is because of discrimination on the part of insurance companies against patients who need psychological care. "These patients are given the 'mental'— not medical— care label and rejected," she explained. She also works with people who have eating disorders and other potentially long-term psychiatric problems. Even when they have health insurance, the rate of reimbursement and the lifetime benefits for psychiatric treatment are substantially less than for medical care. Trisdorfer has known families who have been forced to sell their homes to pay for their children's psychological treatment. She said to legislators, "People suffer and sometimes die from the consequences of psychiatric disorders. Please don't forget them in your health care reform package."

- Douglas Tift, of Warwick, Rhode Island, was a proud welder of the Seawolf submarine before being laid off a year ago. He was able to find a job in the printing industry. Being the father of five children—three of his own plus two foster children—for a time Tift had to choose between paying for insurance or putting food on the table and providing shelter for his family. "This is no choice for a father to make," Tift said. The family has had to deal with several health issues, including the eldest daughter's pervasive developmental disorder and strict limits on what the state will pay for their foster children's health bill. Tift believes in prevention. "Our children are America's future," he said. "It's a crime that all American children, are not immunized. If we can't adequately care for our children, what will happen to America?" Tift believes that "kids are our leaders of tomorrow— our doctors and lawyers of tomorrow. We have to give them the best care we can today." He concluded, "Remember health care; it's a right, not a privilege."

- George Khouri III, 9, of West Columbia, South Carolina, developed Ewing's sarcoma, a cancer in the pelvic region, in 1992. He required multiple diagnostic studies, such as MRIs, bone scans, and blood tests, together with a rigorous course of chemotherapy and radiotherapy resulting in health care bills of tens of thousands of dollars. George's father worked for a self-insured employer who informed him that, in the wake of his son's high health care costs, the company would either have to triple the price of all its workers' premiums or fire George's father. The company chose the latter. Because the employer was self-insured, Khouri did not qualify for COBRA or for help through the South Carolina Insurance Fund, a safety net for families unable to pay their high medical bills. Khouri himself then developed diabetes, so he too has a preexisting condition. The family was only saved from foreclosing on their home to pay their health care bills because they won a lawsuit against the employer who fired Khouri

over the insurance costs. Khouri said that theirs is "a story of where the laws that govern the insurance in our country failed, but the good people of the United States and our community picked up the slack." He continued, "I hope that health care reform will close all the loopholes and allow us to help the distress and the heartbreak."

- Evelyn Mausser of Rapid City, South Dakota, was a nurse for 43 years. Now, however, she needs one because only 19% of her heart is working, and she has high blood pressure and diabetes. On her fixed income she really has to scrimp to pay for her medicine. "You have to choose," she explained. "Do I eat or do I take my medicine? And there's a lot of people who get less Medicare than I do." If it wasn't for her younger daughter and son-in-law, she feels she wouldn't make it. Her older daughter has lupus and no insurance, and those medical bills are more than $250,000. Her son-in-law had saved baseball cards for years; he sold one for $10,000, and that's how they've paid their medical bills. If they hadn't, they would have lost their farm. "We have excellent medical care in the United States," Mausser said, "I know, because I was one of those who provided it, but we need to make it more accessible to everyone, not just a few people."

- Ray Sinor, of Hixson, Tennessee, has a 38-year-old son with schizophrenia, an illness so severe and so in need of its own advocates that Sinor retired at age 56, nine years ago, to become a full-time advocate for and supporter of his son's care. "We have little left to give this boy," he explained to us. "It is frustrating, it is expensive and it is lonely. Schizophrenia has robbed my son of his normal life; it's robbed his mother and me of our energies and our resources." Sinor, a board member of the National Alliance for the Mentally ill, has become an expert on mental health issues. "Very few beds for long-term care are available for the mentally ill in our state and nation. One and one-half million people who are mentally ill are currently housed in our jails across our nation. Thirty-three percent of homeless people are mentally ill. How long must they continue to suffer?" He and his wife worry about what will happen to his son when they are gone. "Parity of care for the mentally ill should be a requirement and not a political compromise," he emphasizes. "Parity and nothing more and nothing less."

- Joyce Heneage, of Houston, Texas, became homeless as a result of the expense of treating—and eventually curing—her cancer. She currently lives and works at a mission for homeless people in Houston. She told us, "Four years ago, I was employed, very proud. I developed cancer. I ended up in the hospital for months and months and months. I was informed by my employers that I could either quit or be fired." Her several cancers required many expensive surgeries. Eventually she was released from the hospital and went home. She went through her life savings, still unemployed. "People who fall through the cracks in the system are treated like pieces of meat, and the level of care is very poor," she said, remembering times when she was one of 50 cancer patients waiting to see two oncologists in a single day. She went from private pay to emergency room to public health care. "Health care and homelessness are bound together," she continued. "We need to devise a system where people come first."

- Travis Carlson, 2, of Bountiful, Utah, was born deaf, blind, and with paralyzed vocal cords. His parents, who were students at the time, had student health insurance. Travis's health care costs quickly reached the cap for their student policy, and they could not receive further benefits. His mother Stephanie says, "Travis is one of the nation's fastest dropped individuals for health insurance. In three weeks, he had capped out his policy and was considered

uninsurable forever." Travis' medical bills are more than $100,000 a year. The Carlsons feel that it is criminal that insurance companies can accept money from the most healthy part of the population for years and years and years and then be justified in dropping people that quickly or at all. Stephanie said, "They are for profits, they are not for health." This family believes that it is very important that legislators develop a health care system that will allow technology to permit handicapped children to remain at home. "That is where they are supposed to be and they should have the right to play and roll on the grass just like any other child, not live in a four-by-four foot square."

- Paula Buckley, of Grand Isle, Vermont, along with her family, has paid into the health care system for decades and never used it. It wasn't until they lost their jobs that they received the best medical coverage of their lives—under Medicaid. She told us, "We paid into the system for more years than I want to talk about. I can't believe that to get proper medical care we had to lose our jobs and have an income under $15,000 a year. We are now the working poor," Buckley explained. "We deliver newspapers." With respect to health care reform, she told legislators, "This is not business as usual. It's immoral. It's disgusting the way millions of people suffer and die just so [people] can profit from special interest groups. They are expendable. We are not." She concluded, "I think our health care system is a disgrace, an absolute disgrace."

- Betty Desper, 74, of Salem, Virginia, was housing director of Total Action Against Poverty for 22 years. She and her husband have been married for 58 years. Her husband had a stroke while driving; subsequent tests revealed that he also suffered from diabetes. For Desper to take care of her husband, she had to leave her job, which meant that they lost not just his income, but hers as well. Desper wanted to care for her husband at home, but after a second severe stroke, the doctor advised that he needed care in a nursing home. She explained, "We paid for modest home. We had a little money in the bank, so we figured when we retired, we would enjoy life a little, the golden years. That didn't happen." The Despers have spent down to be eligible for Medicaid. She said, "Once you go into a nursing home, believe you me, you have nothing. Anybody can be instantly forced into a crisis when loved ones need long-term care."

- Ricky Halsey, 2, from Kent, Washington, was born two months premature with underdeveloped lungs. He almost died shortly after birth; the doctors had given up on him. Ricky has been on a ventilator since. He came home, finally, at nine months of age. The family's medical bills are outrageous, and they have little insurance. His father, Gerry, said, "Washington state is one of a handful of states in this country that supports and pays for home health care. We're so grateful we live in Washington because there is no way, as members of the working—hard-working —poor, that we could pay these kinds of medical bills. We're very fortunate to be low income. Does that makes sense?" Halsey, whose third son had congenital heart disease and died after surgery at four years of age, and whose 20-year-old daughter is mentally retarded, concluded, "Please find a way to take care of all the needs of our children."

- Paul D. Jeffrey, Sr., of Charleston, West Virginia, has seen his wife Irma hospitalized more than 46 times in the past five years. She has suffered heart problems, seizures, severe clinical depression, numerous surgeries, and more. During the first two years alone, her medical bills totaled more than $200,000. Although Jeffrey had a good job with the US Postal Service and had what they thought was excellent insurance coverage, these bills forced the family into

bankruptcy. The Jeffreys have spent the last three years trying to regain their financial footing. "My wife still requires $600 –$700 of medication every single month to keep her viable and alive," Jeffrey explained. "People tell us we are lucky. But if we are lucky, God help those who aren't. My wife and I feel like we've been to hell and back—this while living in the most affluent, technically advanced society on God's earth." Jeffrey feels that universal health coverage is only part of the solution. Health care providers must be charged with providing affordable health care and accepting the insurance payments for it. Jeffrey challenged the lawmakers in Washington "to end this absurd nightmare."

- Sara Ben-Ami, of Madison, Wisconsin, is a mother of two young children. She and her family belong to the 60% of Dane County, Wisconsin, that is uninsured. Their income is less than $25,000 a year. Although they have access to a group health plan through her husband's work as the head chef at a reputable restaurant in Madison, the cost is about $400 per month—one fifth of their pretax income—and would leave the family with an additional expense of 20% of all medical bills. "That's about 28% of our after-tax income," Ben-Ami explained. "We're frugal. We don't want to be a burden, but we don't want to be denied care due a lack of insurance, so we set aside $175 a month towards emergency health care. That's all we can afford." Their income is too high for them to be covered by Medicaid, but not high enough for them to afford insurance. "It's a challenge when you have to pay $250 for doctor checkups and medicines. That's a big chunk out of our income a month." Ben-Ami will begin work again this fall, when her youngest son begins school. Her salary will essentially cover the insurance policies. "Frankly," she admits, "I'm scared. We fall through the cracks of the system."

- Nicholas Neuman, 4, of Sheridan, Wyoming, was born without an esophagus, a condition called esophageal atresia. Shortly after birth, he was transported to the closest large medical center, Denver Children's Hospital, 425 miles away in Colorado. He remained there for seven months, while his parents took turns being with him. Nicholas was found to have congenital anomalies of the larynx, eyes, ears, and skull. He had a tracheostomy, which required frequent suctioning, and a gastrostomy tube for feeding, and he was on continuous oxygen. His prognosis was poor, but after a year the tracheostomy was removed, Nicholas was breathing on his own, and the G-tube was removed. He now eats total nutrition by mouth. His mother smiled, "We think he is a big success. Our insurance companies did not." Nicholas requires many prescription drugs and the combined costs of drugs and hospital charges exceeded the family's $750,000 insurance ceiling. They were dropped from the policy after three months. The family income was too high for Supplemental Security Income, which would have qualified them for Medicaid. His mother said, "My message is, please, when considering health care reform, give us the parents of special needs children the peace of mind, by knowing that our children will be cared for."

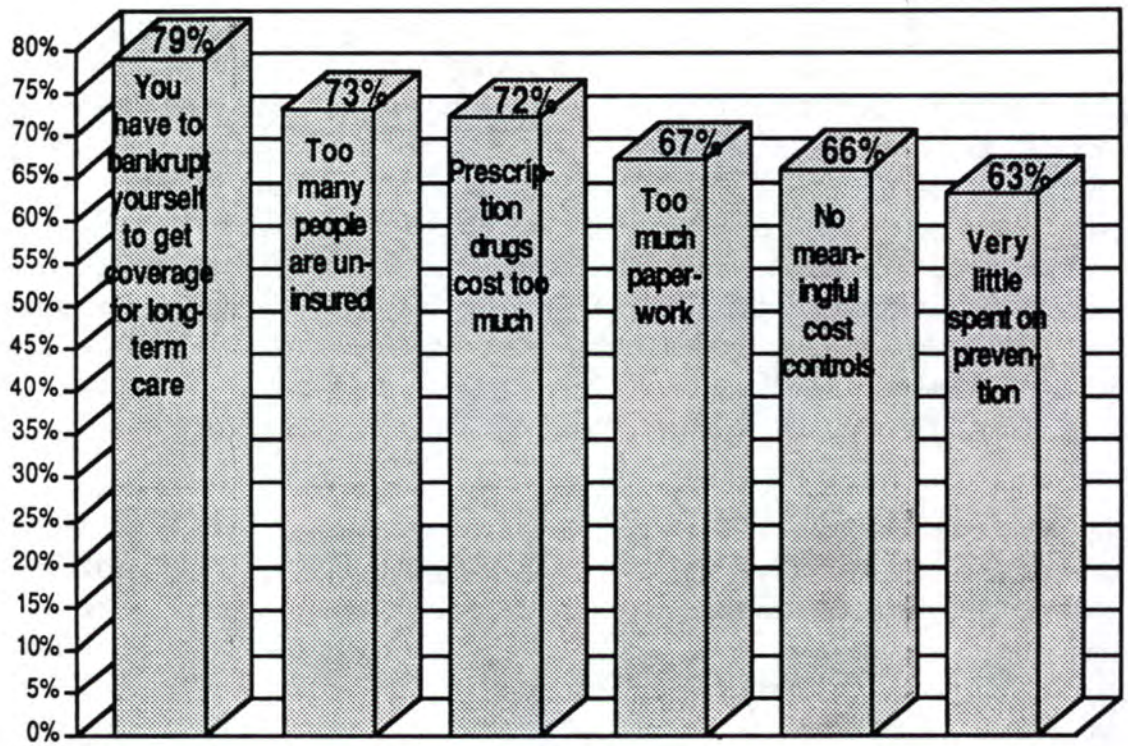
IV. Findings

HealthRIGHT was designed to collect and reflect the will of the people. This process was painstakingly representational, including the opinions of every interested participant regardless of sex, race, religion, level of education, health, or economic status. In combination these people present an eloquent and united plea for health care reform.

The principle recurring themes expressed by the thousands of Americans HealthRIGHT interviewed include the following:

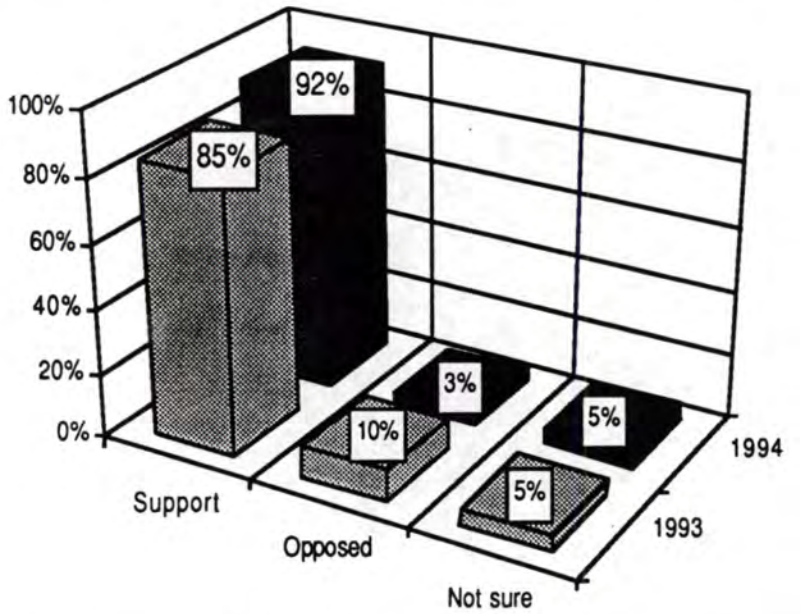
• Virtually no one HealthRIGHT spoke to was satisfied with the existing health care system. Although some people are pleased with aspects of American health care and justifiably proud of the quality of care available in this country, almost everyone expressed a belief that the system could be significantly improved.

What is wrong with the American health care system?



• Over 95 percent of those interviewed by HealthRIGHT expressed a belief that access to adequate health care is a fundamental right. Many people related health care to civil rights in its urgency and importance. Others indicated a belief that the absence of a national health care system diminishes the value of other rights guaranteed by the Constitution.

Should health care be a basic right for all Americans?



- More than 95% of those interviewed favored universal access to health care. Generally, support for this measure was expressed with the understanding that universal coverage is a predicate to establishing any truly national health care system.

- Nearly everyone (98%) expressed support for preventative services and placed emphasis on preventative care.

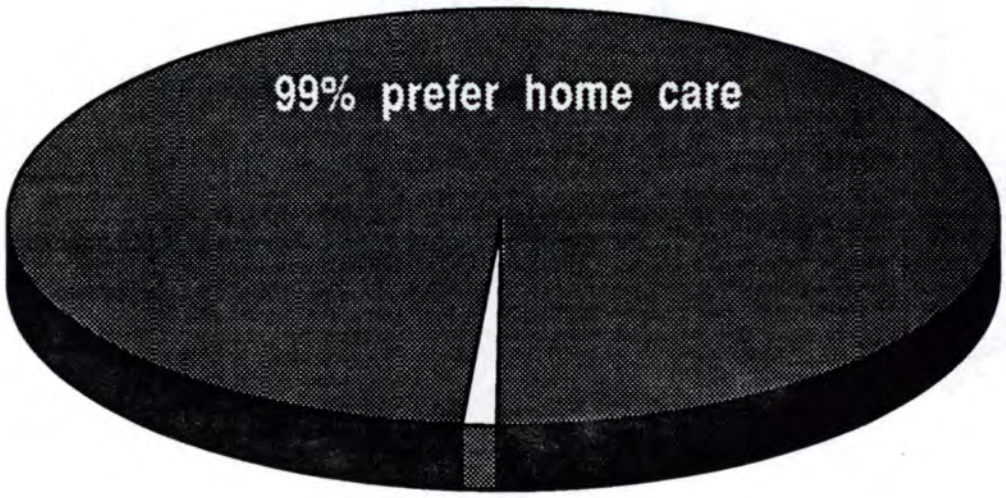
- When asked about long-term care, more than 75% of those interviewed expressed support for this benefit. For many of those expressing support, provision for long-term care was their highest single priority.

- Most Americans view health care as seamless. They neither understand nor appreciate the distinction between short-term, acute illness and chronic conditions requiring long-term care. By and large, the distinction between long-term care and acute care is viewed as an arbitrary and frustrating creation of the insurance community.

- The vast majority of Americans (more than 90 %) want a comprehensive program that includes preventative services and long-term care. Often, support for this position was expressed by indicating a belief that this nation should be able to provide for its citizens at least the same rights available to the citizens of every other industrialized nation in the world.

- The American public supports the expansion of home care, respite, and day care services as the best solutions for dealing with the devastating problem of long-term care. Ninety-nine percent of those interviewed stated they would prefer their chronically ill relative to be cared for in their own home rather than a nursing home.

Where do you prefer your chronically ill relatives to be cared for?

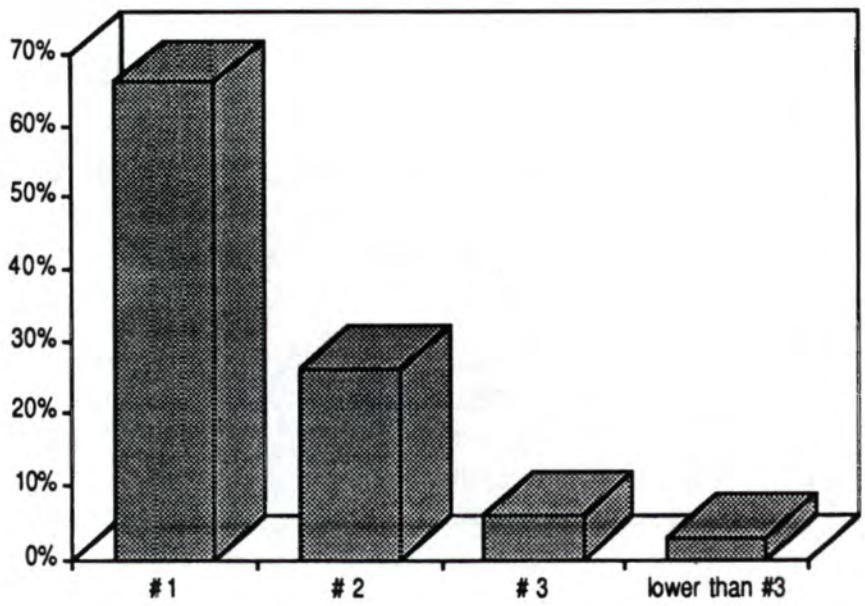


1% prefer nursing home care

- The right to chose physicians and other caregivers is still important to the majority of Americans (more than 70%).

- The vast majority of Americans (more than 95%) indicated health care reform should be a high priority. Health care reform consistently ranked as the first or second priority. The reason most often stated for this priority is the belief that health care affects everyone in our society.

Should health care be #1 on the nation's list of priorities?



- Most people expressed a willingness to pay for greater health care, particularly if the payment was dedicated and discrete. Sin taxes, in particular, (taxes on alcohol, tobacco, firearms, and munitions) are widely supported (75+%).

- There is widespread dissatisfaction (more than 90%) with the organization and administration of US health care programs. Those who were ill or had been ill repeatedly told HealthRIGHT that dealing with illness is tough enough without having to make sense out of the system and deal with the demands of insurers. Caregivers and health care professionals agreed the most frustrating part of their role had to do with the amount of time and energy diverted from patient care to deal with administrative duties and paperwork.

There is wide dissatisfaction with insurance companies and their role in health care. Insurers were commonly cited as inhibiting rather than aiding the delivery of appropriate care. Individuals also frequently said they increase administrative costs beyond reason and profit beyond justification.

Overall, the HealthRIGHT tour provided a sense of just how smart the American people are and how well they understand the issues facing our society. One respondent spoke for many when he summarize his position: "We really don't have a health care problem," he responded. "What we have is *political* problem."

The absence of a comprehensive health program was repeatedly cited as a leading example of the government's unresponsiveness to the people. To many Americans, the absence of an equitable national health care program is quite simply immoral and wrong. There is a broad consensus that the costs associated with the failure to establish a national health program is undercutting business's ability to compete, adding to the deficit, destroying families, and eroding the soul of our society.

V. Further Validation

HealthRIGHT has commissioned public opinion polls by Louis Harris and Associates and by the Gallup Organization that substantially support its findings. In February 1993, Louis Harris released a poll that examined the attitudes of Americans toward their own health, the quality of health care they received, their view of the major options for reforming the health care system, and their priorities for health care. Harris presented his report to the House Select Committee on Aging. He also hand-delivered a copy of the poll to Hillary Rodham Clinton and to Department of Health and Human Services Secretary Donna Shalala.

The Harris poll showed a general dissatisfaction among the American public about the way health care is financed; a desire to go beyond partial solutions to health care reform, but instead to engage in meaningful, comprehensive reform; and a real commitment to long-term care, especially home care and preventive medicine. "What all this ads up to," said Harris in his report, "is a mandate for basic change in the country's health care system, change that builds on existing quality but fundamentally alters the way services are delivered and financed." Other poll results include the following:

- Strong preference for home care over nursing home care. Some 50% of the American public said that they, a member of their family, or someone they have known has needed long-

term care. By an overwhelming 79% to 14% the American public says it prefers long-term home care to long-term nursing home care.

- Deep concern about the cost of long-term care. Ninety-one percent of Americans said they could not afford long-term care; 7% said they could. This is even greater than the 82% to 16% margin recorded in 1988.
- Strong support for federal programs to provide long-term care for the chronically ill in all age groups. Of those 65 years and older, 88% of respondents say they favor such a program; for those 20–64 years old, 83%; for those 19 and under, 86%.
- Support for extending Medicare tax to earnings over $130,200. By an 81% to 15% margin the public favors such an approach to fund a program for long-term care.
- High priority for long-term health care. Some 31% say long-term health care should get the highest priority, while 54% say it should get a high but not top priority; only 11% say it should get a lower priority.

All in all, the American people were far ahead of their political leaders on health care reform. They were not looking for piecemeal change. They wanted, and still want, fundamental reform—with a choice of doctor and hospital, but based on national health insurance—*not* managed care, a pay-or-play plan, or managed competition. Long-term care, with home care the preferred form of assistance, has strong support, along with preventive medicine and the need for caring hospitals, in a revised health care system.

In June 1993, the Gallup Organization released its report of a poll on American's attitudes about methods of paying for a national health care system, including long-term care. The poll demonstrates conclusively that the American public is willing to pay for a comprehensive system of health care insurance, provided that such taxes are broadly based, progressive, and discrete. The public is putting a premium on value received; this equates in the polls with the question as to whether and to what extent the new plan includes meaningful coverage for long-term care.

Highlights of the Gallup poll are included below. In summary, the taxes that were supported by greatest percentage of Americans, in descending order, were the following:

- a tax increase on alcohol.....75% in favor
- a tax increase on guns.....72%
- a tax increase on cigarettes.....68%
- a value-added tax (VAT) on goods sold in the United States but not produced here.....67%
- a tax on noncritical health services....66%

The taxes that were least supported include the following:

- a 1% excise tax on all health insurance claim benefits paid to individuals .....27% in favor
- a 7% VAT on all products.....20%

Respondents were evenly split in their support of two additional suggestions:

- a 1% tax on all revenues received by hospitals .....51% in favor
- reducing the employer tax deduction for health care contributions.....53%

Respondents aged 18–34 (57%) and those with incomes of between $35,000 and $50,000 (56%) were most likely to support the one percent tax on hospital revenues, as well as a reduction in the tax deduction for employer contributions to health care plans. Respondents with incomes of more than $50,000 (45%) and those aged 55 and over (43%) were least likely to support either the hospital tax or the reduction in the employer deduction.

There were no significant statistical differences in support of these measures by gender, with two exceptions. Males (63% in favor) were less likely to support a 10% tax on the purchase of guns than females (79%). Additionally, males (70% in favor) were less likely to support a 10% increase in taxes on alcoholic beverages than females (80%).

The results of this poll lend weight to the President's decision to capture what employers and employees are presently paying for health care, and thereafter to supplement with so-called sin taxes, such as tobacco and alcohol taxes.

VI. Conclusions

All too often the discussion of health care reform focuses on numbers. The health care debate, like the health care system, has focused on the cost of care and the financial interests of the constituencies with a vote. Too often in this debate over what services will be covered and what it will cost, the people have been forgotten.

HealthRIGHT was established in the belief that health care is about people. HealthRIGHT's mission is to put faces on the numbers and to give the people a voice. Over the course of the last three years, HealthRIGHT has traveled from coast to coast to listen to the people and record their views. With the conclusion of the next leg of its journey on August 4, 1994, this unprecedented and heroic effort took the HealthRIGHT crew to more than visiting 150 major cities and thousands of smaller ones, some several times, all 50 states, and a combined distance equal to circling the world twice.

In the process, HealthRIGHT has interviewed people of all ages in all kinds of places. HealthRIGHT spoke with people on the street, in shopping malls, in hospitals, hospices, and other health facilities. HealthRIGHT attended dozens of professional meetings, social gatherings, civic events, and commercial centers. HealthRIGHT has interviewed literally thousands of people—professionals and politicians, doctors and nurses, the young and the old, the sick and the well. These people were asked what they thought of the US health care system and were asked to express their concerns as part of the first ever video petition to Congress and the President.

When the comments HealthRIGHT received are reviewed, the first and most striking conclusion is this: No one is satisfied with our health care system. Even the strongest proponents or our existing health care system concede we can do better.

Second, HealthRIGHT was surprised at the forcefulness of many of the statements received and the amount of frustration the people expressed. Health care is clearly one of those issues about which the American people feel their leaders have not been listening to them.

Third, the vast majority of the American people want a comprehensive program that includes preventative services and long-term care. Much of the frustration related particularly to the absence of long-term care and the hardship this has created.

Fourth, there is widespread dissatisfaction with the organization and administration of our health care programs. Sick people told HealthRIGHT repeatedly it's tough enough being sick without having to make sense of out of this nonsense. Health care professionals universally said the most frustrating part of their job had to do with the amount of time and energy they had to divert from patient care in order to deal with the insurance carriers.

Fifth, the people interviewed believe it is time Congress structured a program based on their needs. They feel the existing system too often focuses on the needs of the medical community, health care providers, and the bureaucracy, while the needs of the general public are ignored.

Sixth, an overwhelming majority of the people believe health care reform should be a very high priority. The most common expression of this issue was: "This issue affects everyone."

Seventh, the absence of a comprehensive health program was repeatedly cited as an example of the unresponsiveness of our government to its people. To many Americans, the absence of an equitable national health program is quite simply immoral and wrong.

The American public remains positive and confident that an acceptable plan can be established. The common expression was, "If we can find a way to fly to the moon, we can surely do what so many other countries have done and provide health care to all Americans."

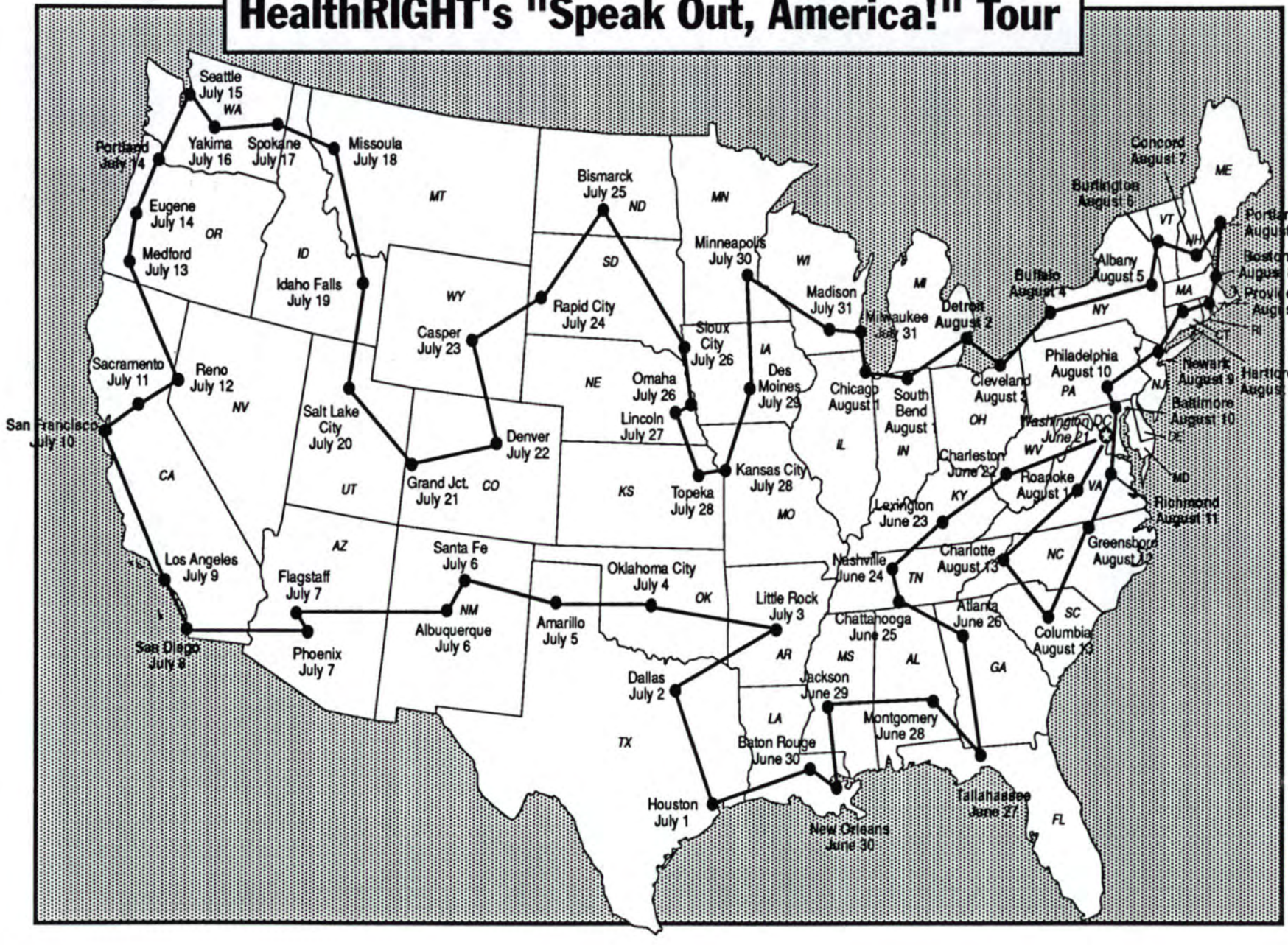
Finally, the American public sees health care as a moral and not simply as a political and economic issue. They remember President John F. Kennedy, who quoted the historian Arnold Toynbee in his advocacy of the Medicare Act. Toynbee, said Kennedy, had conducted detailed studies and concluded that one could predict the greatness and durability of a society by a common yardstick. This was the manner in which each civilization cared for the aged, ill and disabled. Therefore, Kennedy said, it was not a question of whether the nation could afford health care for the elderly— it was a question of whether we could afford not to provide it. What was at stake, said Kennedy, was America's very future, in the way that the United States would be judged through the prism of history. The public overwhelmingly believes that what Kennedy said in 1963 is even more valid today, in the context of the enactment of a national health insurance plan.

Appendix: HealthRIGHT's Tours

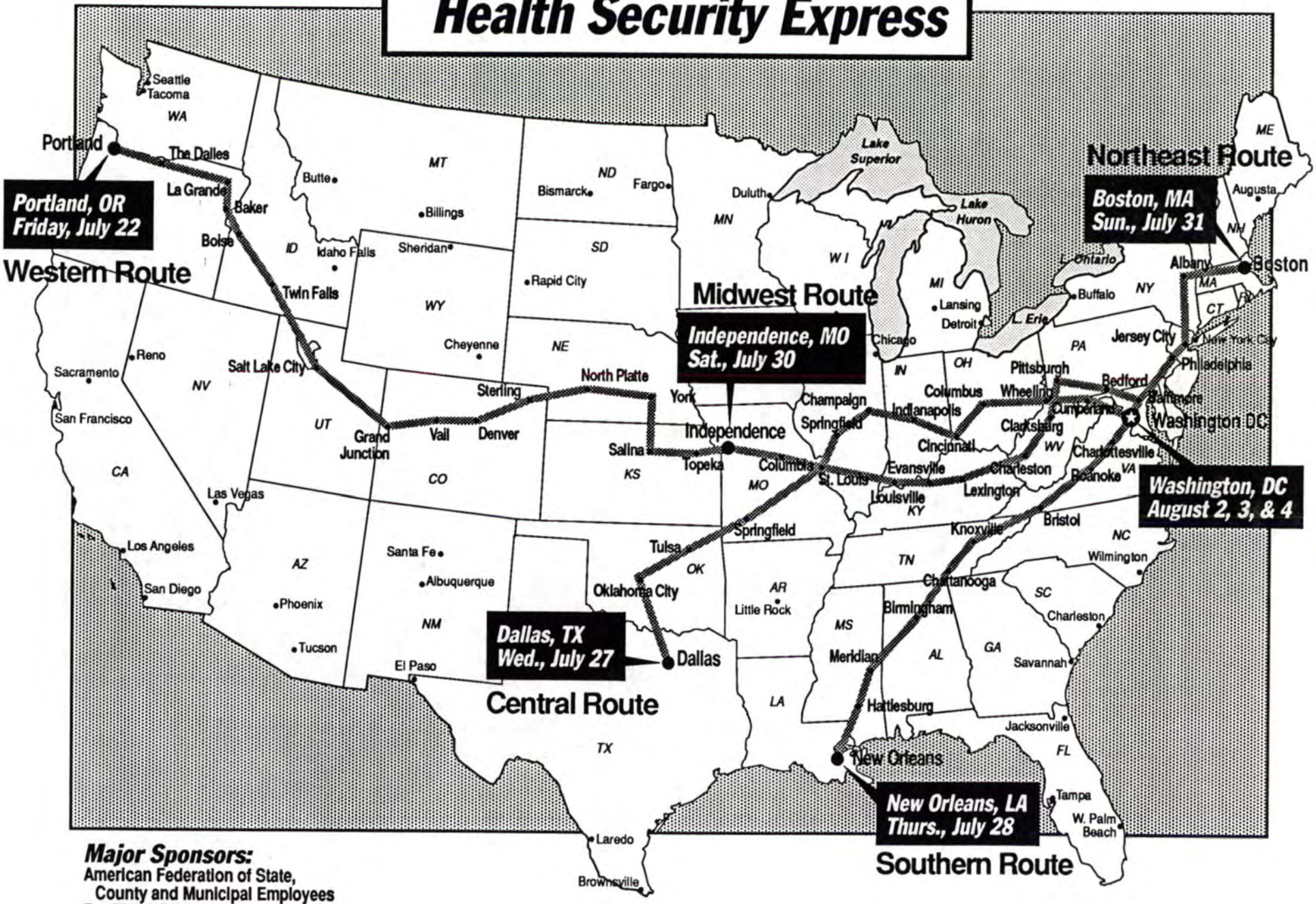
The three maps that comprise this appendix illustrate three of the four major national tours that, as noted above, HealthRIGHT has conducted.

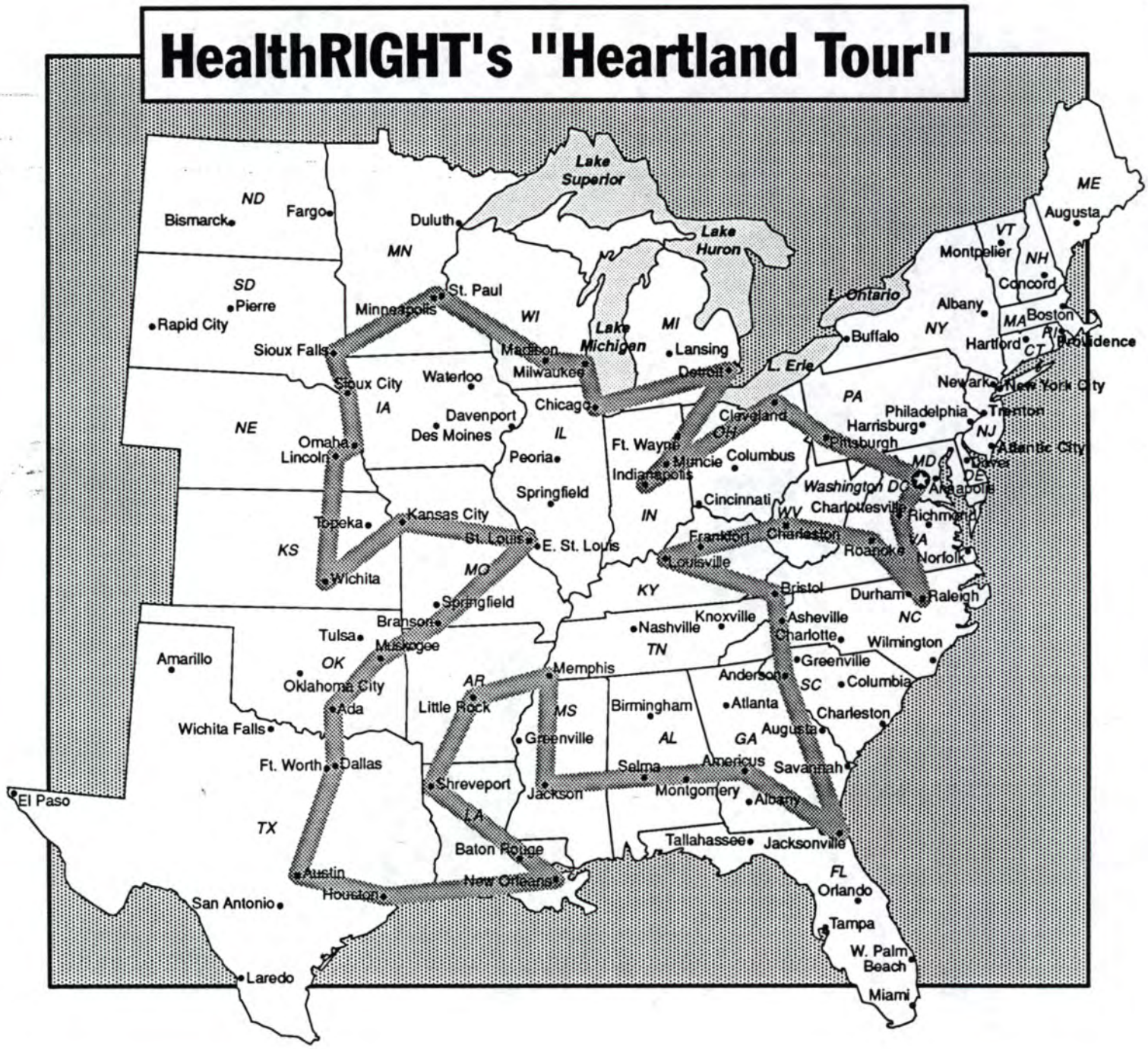
- HealthRIGHT's first tour was conducted across 10 states in summer 1992, covering 8,000 miles. (No map was produced to illustrate this first effort.)
- HealthRIGHT's second national tour, entitled "Speak Out, America!" was a 16,000-mile odyssey into all 50 states and the District of Columbia, which began in June 1993 and was completed in September.
- In June 1994 HealthRIGHT began another major tour called "The Heartland Tour." It covered 26 states in America's heartland. HealthRIGHT traveled more than 11,000 miles, visiting more than 40 major cities to collect the views of the American public on videotape.
- HealthRIGHT joined as one of three major sponsors of another national bus tour, called the "Health Security Express." This caravan of buses traveled from every corner of the United States to converge on Washington, DC, on August 3 and 4. These buses traveled an additional 10,000 miles, and at every step along the way, HealthRIGHT cameras recorded the voices and opinions of the American people.

HealthRIGHT's "Speak Out, America!" Tour



Health Security Express




HealthRIGHT's "Heartland Tour"
Lake Superior
Lake Huron
Lake Michigan
L. Erie
L. Ontario
ND
Bismarck
Fargo
Duluth
MN
SD
Pierre
Rapid City
Minneapolis
St. Paul
WI
MI
Sioux Falls
Madison
Milwaukee
Lansing
Detroit
Sioux City
Waterloo
IA
Chicago
Davenport
NE
Des Moines
IL
Omaha
Lincoln
Peoria
Ft. Wayne
Cleveland
OH
Pittsburgh
Buffalo
NY
Albany
Springfield
Indianapolis
Muncie
Columbus
Cincinnati
Topeka
Kansas City
St. Louis
E. St. Louis
KS
IN
WV
Charleston
Charlottesville
Richmond
Washington DC
MD
Annapolis
DE
Dover
Frankfort
Louisville
VA
Roanoke
Norfolk
Wichita
MO
KY
Springfield
Bristol
Durham
Raleigh
Branson
Nashville
Knoxville
Asheville
NC
Tulsa
Muskogee
TN
Charlotte
Wilmington
Amarillo
OK
Memphis
Greenville
Oklahoma City
AR
Anderson
SC
Columbia
Ada
Little Rock
MS
Birmingham
Atlanta
Charleston
Wichita Falls
Greenville
AL
GA
Augusta
Ft. Worth
Dallas
Selma
Americus
Savannah
Shreveport
Jackson
Montgomery
Albany
El Paso
TX
LA
Baton Rouge
Tallahassee
Jacksonville
Austin
New Orleans
FL
Houston
Orlando
San Antonio
Tampa
W. Palm Beach
Laredo
Miami
ME
Augusta
VT
Montpelier
NH
Concord
MA
Boston
RI
Providence
CT
Hartford
NJ
Newark
New York City
Trenton
Atlantic City
PA
Philadelphia
Harrisburg