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Budget - FY [Fiscal Year] 2000 - Community Requests - CAEAR [Cities Advocating Emergency AIDS Relief] Coalition

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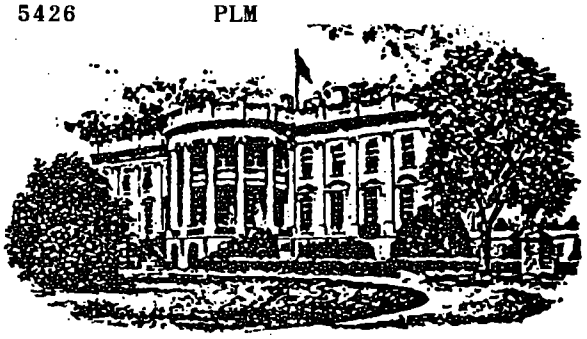

THE WHITE HOUSE

WASHINGTON

FACSIMILE FROM: MATT PITCHER
OFFICE OF PRESIDENTIAL LETTERS AND MESSAGES
OLD EXECUTIVE OFFICE BUILDING, ROOM 97

VOICE: (202)456-5517 FAX: (202) 456-5426

NUMBER OF PAGES (INCLUDING COVER): 5

DATE: 12/4/98

TO: Todd Summers

VOICE: _____

FAX: 6-2434

[X] INCOMING LETTER(S) FROM: The CAEAR Coalition

RE: CARE ACT Funding increases

[X] FOR YOUR REVIEW

[X] PER MY E-MAIL OR VOICE-MAIL MESSAGE TO YOU

[ ] PER YOUR REQUEST

ADDITIONAL COMMENTS:

Thanks! I'll have my draft ready for your review ASAP.

#282471

CAEAR
CITIES ADVOCATING EMERGENCY AIDS RELIEF

October 16, 1998

The Honorable William J. Clinton
President of the United States
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear Mr. President:

Cities Advocating Emergency AIDS Relief (CAEAR) is a national grassroots coalition advocating on behalf of people living with HIV disease who depend on Title I and Title III of the Ryan White CARE Act for health care and support services. We include members of Title I planning councils, people living with HIV/AIDS, community-based AIDS service organizations, providers of HIV health care, CARE Act grantees and consortia. We are civic and business leaders, lesbians and gay men, members of religious organizations, government representatives, local public health officials, drug treatment and mental health providers, and representatives from diverse communities of color.

We write to you today to ask that you request FY 2000 budget increases for all CARE Act programs, and in particular, we strongly urge you to include in your FY 2000 budget a request to Congress for $620 million in funding for Title I of the CARE Act and $131 million in funding for Title III of the CARE Act.

Increased funding for the CARE Act is urgently needed to address the AIDS emergency in communities across the nation. The increases referenced in this letter are based on the expectation that Congress will provide in FY 1999 $500 million in total funding for Title I and $91 million in total funding for Title III.

The AIDS epidemic in America has continued to grow, relentlessly spreading to new communities and especially now to historically underserved populations which have severe social, economic, and health problems. In FY 1991, Title I provided assistance to 16 communities. In FY 1999, 51 American metropolitan areas will receive funding under Title I. These 51 communities account for 74 percent of all reported AIDS cases in America. For FY 2000, there may be as many as three newly eligible Title I areas.

In FY 1998, fifteen Title I areas lost funding as compared to the previous year. Despite modest increases in CARE Act funding overall, some, though not always the same Title I communities have lost funding in three of the last four fiscal years as compared with their previous year funding. To keep pace with this expansion of the epidemic to new communities and the loss of funding to existing Title I areas, the CAEAR Coalition is requesting a $7 million increase in Title I funding.

Overall rates of new HIV infections are remaining stable while HIV-related deaths dramatically decline. This means increasing numbers of people with HIV/AIDS are seeking services. A 1998 CAEAR Coalition study reveals an average increase of 43.5% in the number of HIV/AIDS patients between 1995 and 1997.

In 1998, the U.S. Public Health Service issued guidelines for the prevention of opportunistic infections, the use of anti-HIV medications for adults and adolescents and for the use of anti-HIV drugs in pregnant women to reduce perinatal transmission of HIV. Funding remains inadequate to assure the delivery of the standard of care required by these federal guidelines to all who need it.

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OCT 23 [illegible]

With the availability of combination drug therapy, many people with HIV have sought care for the first time. The Health Resources and Services Administration (HRSA) estimates that 20% of Title I clients are new clients. Title I communities across the country have documented client increases ranging from 13% to 74% . Title III programs, currently 183 in all, are found in 43 states and serve more than 85,000 individuals. One-third of Title III patients each year are new patients.

Aggregate Title I requests for funding in FY 1998 were $519,086,004, but aggregate funding was almost $74 million less. The federal government has already approved $11 million to 28 qualified Title III applicants, but cannot fund these applications due to a lack of funding. Twenty-three percent of Title III programs report being the only HIV medical outpatient program in their area. The CAEAR Coalition is requesting an increase of $52 million for Title I and an increase of $11 million for Title III of the CARE Act to address the unmet need for care in these communities.

Both the cost and the complexity of the care provided by Title I and Title III programs is increasing. New therapies have placed significant pressure on Title I and Title III communities to ensure that access to these drugs is available and continuous. These new therapies cannot be provided outside the context of overall primary care. Patients need a coordinated medical team that includes higher levels of expertise among nurses, pharmacists, mid-level practitioners and case managers. Care teams must also include ongoing education about adherence to combination drug regimens. Failure to take these medications as prescribed runs the risk of rapid development of resistant viral strains.

These changes in standard practices for providing HIV care have increased the time needed for each medical visit. The 1998 CAEAR Coalition study shows that from 1995 to 1997 the average length of medical visits increased 65%.

The flood of new clients entering Title I and Title III programs requires more and longer medical visits and social services, including an initial assessment, diagnostics and the determination of a treatment regime. Once treatment is begun, patient education and ongoing monitoring, including expensive viral load testing, is required for all clients. The 1998 CAEAR study estimates that between 1995 and 1997 the total number of patient visits increased by 55.3% and the number of visits per patient rose 27.4%.

The same CAEAR study revealed that from 1995 to 1997 the average cost of HIV medical care rose 89.3%. Various studies indicate that the cost of HIV care would have escalated even higher without the reduction in emergency care and inpatient hospitalization resulting from Title I and Title III programs -- which in some locales have lowered hospitalization admissions by as much as 75% since 1996.

Title III grantees have reported to HRSA that over $5 million was needed but not available for providing case management services to patients in 1996. They also have reported that the cost of providing case management services increased 55% between 1995 and 1996 in part due to an emerging model of case management stressing adherence to complex drug regimens.

The CAEAR Coalition is seeking an increase of $48 million for Title I and an increase of $12 million for Title III to address the increasing cost of HIV care. The Coalition is seeking an additional increase of $7 million for Title III specifically to meet the increasing cost of providing HIV social services.

Approximately two-thirds of Title I and Title III clients are people of color. However, their utilization patterns of medical care and treatments continue to lag significantly behind their representation in local epidemics. Communities of color experience cultural and environmental barriers to full access to HIV health services. Many people of color living with HIV are burdened by histories of other sexually transmitted diseases as well as substance abuse, mental illness, homelessness and tuberculosis. The combination of these factors often results in difficulties in

accessing health care and support services. The need is expanding for outreach to HIV-infected people of color to ensure they are linked into the health care system as early as possible. Delayed access to care perpetuates the disparities in health outcomes and the rate of reduction in AIDS mortality rates. To address the disparities in outcomes, access and in the utilization of care by people of color, the CAEAR Coalition is requesting an increase of $13 million for Title I and an increase of $10 million for Title III.

The AIDS epidemic has produced dangerous strains on our nation's public health systems. Hospitals have long reported significant losses in caring for AIDS and HIV patients. Despite the recent reductions in hospitalization days and length of stay, the average hospital reports losses exceeding $2,000 per patient per year. As the burdens mount, responding to the needs of the AIDS epidemic grows more difficult and imperils our ability to meet all the other health needs in our communities. Heavily reliant upon funding for all titles of the CARE Act, our communities request that your budget include adequate funds for all titles of the CARE Act, as well as other federal AIDS efforts in prevention, housing and research.

With funds provided under the Ryan White CARE Act, our communities can prolong the lives of people with AIDS and save the nation millions of dollars in unnecessary hospitalizations and other health care costs. A study has shown that patients with case-managed care, such as that provided with Title I and Title III funding, realize 46% lower hospitalization costs and live 66% longer than people with AIDS not receiving case-managed care. Proper care and supportive services enables people with AIDS to remain working and contributing to their communities.

With Title I and Title III funds, we can save money as well as maintain the health and improve the quality of life for people with HIV/AIDS, but we need your help to do it. Please give people living with HIV/AIDS, their caregivers, family, friends and communities your continued support.

Sincerely,

Matthew McClain
Philadelphia, Pennsylvania
Chair, CAEAR Coalition

Suzi Rodriguez
Los Angeles, California
Vice Chair

Marc Haupert
Los Angeles, California
Treasurer

Heidi Nelson
Chicago, Illinois
Title III Representative

Tracy Fischman
Chicago, Illinois
Title III Representative

Al Ballesteros
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Southwestern Regional Representative

Pat Bass
Philadelphia, Pennsylvania
Mid-Atlantic Regional Representative

Jacque Muther
Atlanta, Georgia
Southern Regional Representative

Dr. A. Gene Copello
Jacksonville, Florida
At-Large

Daryl Flynn
Los Angeles, California
At-Large

Harold Cox
Boston, Massachusetts
At-Large

Sue Geissler
Denver, Colorado
At-Large

Ernest Hopkins
San Francisco, California
At-Large

GOVERNMENT AND PUBLIC RELATIONS

THE Sheridan GROUP

FAX TRANSMITTAL

DATE: November 24, 1998

TO: Todd Summers

FAX #: 456-2438

FROM: Grayson Fowler

____PAGES INCLUDING COVER SHEET

1808 SWANN STREET NW • WASHINGTON DC 20009
phone 202.462.7288 *fax* 202.483.1964

CAEAR
CITIES ADVOCATING EMERGENCY AIDS RELIEF

$625 MILLION NEEDED IN FY 2000 FOR CARE ACT TITLE I

For FY 2000, the CAEAR Coalition seeks an increase of $120 million for a total of $625 million in funding for Title I of the Ryan White CARE Act. Title I of the CARE Act provides emergency assistance to the 51 metropolitan areas most heavily impacted by the AIDS epidemic to support comprehensive HIV health care and treatment for the increasing number of low-income uninsured and underinsured persons living with HIV/AIDS. An estimated 74 percent of people in the U.S. diagnosed with AIDS reside and receive their health care in Title I areas. During FY 2000, an estimated 156,000 people with HIV will be served by CARE Act Title I programs.

Need for HIV Primary Medical Care Escalating

For FY 2000, the CAEAR Coalition seeks an increase of $52 million to provide HIV primary medical care for existing clients and uninsured and underinsured people living with HIV/AIDS coming into care for the first time.

- Title I is the safety net for thousands of low-income people living with HIV/AIDS who live in metropolitan areas and are ineligible for entitlement programs. Most of these individuals have severe social and economic problems that complicate their ability to manage their HIV disease. The majority of Title I clients are dually or triply diagnosed with substance abuse and mental illness in conjunction with HIV/AIDS.
- The aggregate Title I requests to the Health Resources and Services Administration (HRSA) for funding in FY 1998 were $519 million; actual Title I grants in FY 1998 totaled $445.1 million -- almost $74 million less than the need.
- Primary medical health care services and transfers to the AIDS Drug Assistance Program (ADAP) account for 69% of Title I service funding, 59% and 10% respectively.
- Overall rates of new HIV infections are remaining stable while HIV-related deaths dramatically decline. This means that increasing numbers of people living with HIV/AIDS are seeking services. A 1998 CAEAR Coalition study indicates an average increase of 43.5% in the number of people living with HIV/AIDS receiving services between 1995-97.
- In 1998, the U.S. Public Health Service issued guidelines for the prevention of opportunistic infections, the use of anti-HIV medications for adults and adolescents and for the use of anti-HIV drugs in pregnant women to reduce perinatal transmission of HIV. Title I funding remains inadequate to assure the delivery of the standard of care required by these guidelines to all eligible people living with HIV/AIDS in Title I areas.
- The availability and success of combination drug therapies have motivated many people living with HIV/AIDS to seek care for the first time. In FY 1998, HRSA estimated that 20 percent of Title I clients were new to care.

Cost and Complexity of HIV Care Increasing

For FY 2000, the CAEAR Coalition seeks an increase of $48 million to address the increasing complexity and cost of delivering quality HIV medical care.

- Advances in HIV/AIDS care requires more and longer medical visits, including an initial assessment, diagnostics, including expensive viral load testing, and the determination of a treatment regime. A 1998 CAEAR study found the average length of medical visits increased 65% from 1995-97, and the average cost of medical care rose 89.3%.
- Once treatment is begun, patient education and ongoing monitoring are required. A 1998 CAEAR study estimates that between 1995-97 the total number of patient visits increased by 55.3% and the number of visits per patient rose by 27.4%.

- More than ever, people in care need a coordinated medical and support service plan that includes higher levels of expertise among doctors, nurses, pharmacists, case managers and peer advocates. Care teams must develop plans that include ongoing education about the importance of adherence to combination drug regimens to prevent resistant strains of HIV and regular updates on new treatment developments.
- CARE Act services have significantly reduced the costs of medical care by reducing the amount of hospital-based emergency and inpatient care being provided to people living with HIV/AIDS.

Outreach to People of Color

For FY 2000, the CAEAR Coalition seeks $13 million to address the disparity in outcomes, access, and in the utilization of care and treatment by people of color living with HIV/AIDS.

- About 64% of Title I clients are people of color. However, their utilization patterns of medical care and antiretroviral treatments continue to lag significantly below their representation in local epidemics. Many people of color living with HIV/AIDS are burdened by co-morbid factors such as other sexually transmitted diseases, substance abuse, mental illness, homelessness, poverty, tuberculosis and a lack of education. The combination of these factors often results in difficulties in accessing health care and support services, which perpetuates the disparities in health outcomes and slows the reduction in AIDS deaths in racial and ethnic minority communities.
- The FY 1999 Title I appropriation included $5 million for targeted planning grants serving African American communities disproportionately impacted by the epidemic. This funding must be maintained and expanded in FY 2000.
- The largest number of new infections for both females and males in 1996 were among African Americans.

New Title I Metropolitan Areas -- Existing Areas Continue To Lose Funding

For FY 2000, the CAEAR Coalition seeks an increase of $7 million to address the addition of new Title I eligible metropolitan areas and a loss in funding to existing Title I areas.

- There may be as many as three new Title I metropolitan areas eligible for FY 2000.
- In FY98, fifteen Title I areas lost funding as compared to the previous year. Despite modest increases in CARE Act funding overall, some, though not always the same, Title I communities have lost funding in three of the last four fiscal years compared with their previous year funding.

Complete citations of data sources are available upon request.

For further information, contact the CAEAR Coalition,
1413 K Street, NW, Suite 700, Washington, D.C. 20005, 202.789.3565, fax 202.789.4277; or
The Sheridan Group, 1808 Swann Street, NW, Washington, D.C., 20009, 202.462.7288, fax 202.786.1964

CAEAR
CITIES ADVOCATING EMERGENCY AIDS RELIEF

$134 MILLION NEEDED IN FY 2000 FOR CARE ACT TITLE III

For FY 2000, the CAEAR Coalition seeks an increase of $40 million for a total of $134 million in funding for Title III of the Ryan White CARE Act. Title III of the CARE Act provides grants directly to 179 community-based clinics and public health providers in 39 states plus Washington, D.C. and Puerto Rico to develop and deliver both early and ongoing comprehensive HIV medical services to more than 85,000 persons with HIV/AIDS, on an outpatient basis. On average, each of these community-based, HIV primary care programs provide early diagnosis and treatment to over 450 clients. Title III ensures a rapid clinical response to ever-changing medical treatment practices and a means to address inadequacies in primary care services, particularly in poor areas, smaller cities and rural communities.

Increasing Cost of Primary Health Care

For FY 2000, the CAEAR Coalition seeks an increase of $12 million for the increasing costs of providing primary health care services to more than 85,000 individuals.

- A 1998 CAEAR Coalition study indicates that between 1995-97 the average cost of medical care per patient rose 89.3%.
- The CAEAR study also reported that between 1995-97 there was an average increase of 43.5% in the number of HIV/AIDS patients seeking services.
- In 1996, over 30% of all Title III patients were new patients, who require intensive and complex medical care, including an overall medical assessment, viral diagnostics, and a stabilizing anti-AIDS treatment regimen.
- Recently, the standard care for people with HIV/AIDS has been altered to promote wellness and adherence to new and complex drug regimens. This has required intensive client education, intervention, and ongoing support. A 1998 CAEAR study revealed that between 1995-97, the total number of patient visits increased by 55.3% and the average number of visits per patient increased by 27.4%, primarily to monitor the efficacy of and adherence to complex regimens and to provide quarterly viral load testing.
- Changes in the HIV standard of care have also increased the amount of time needed for each visit per patient. A 1998 CAEAR study revealed that between 1995-97, the average length of medical visits increased by 65%.
- Over 73% of all new Title III patients in 1996 entering the health care system were moderately to severely ill and in great need of health care services.
- The overall cost of providing access to HIV-related primary care would have escalated even higher without the early diagnosis and treatment provided by Title III programs. Title III programs have reduced hospital admissions in some locales by as much as 75% since 1996.

Outreach to People of Color and Other Underserved Communities

For FY 2000, the CAEAR Coalition seeks an increase of $10 million for outreach and care for people of color and other underserved communities who have historically lacked access to the health care system.

- The FY 1999 Title III appropriation included $3 million for targeted planning grants serving African American communities disproportionately impacted by the epidemic. This funding must be maintained and expanded in FY 2000.
- Two-thirds of the patients served by Title III grantees in 1996 were people of color.
- One-third of the patients served by Title III grantees in 1996 were women.

- The largest number of new infections in males in 1996 were among African Americans.
- The largest number of new infections in females in 1996 were among African American women; the second largest increase for females was among Hispanic women.
- Outreach to HIV-infected people of color must be expanded in order to ensure early access to the health care system. Delayed care accounts for much of the disparity in health outcomes for historically underserved racial and ethnic minority communities.
- In 1996, 3% of all individuals tested by Title III grantees were HIV positive; for the homeless, this rate was 8%. The rate for the U.S. population at large was 0.26% to 0.36%.
- In 1996, the return rate for post-counseling among those who tested positive for HIV was 99%. This remarkably high return rate reflects the effectiveness of aggressive outreach by Title III grantees.
- In 1998, the National Medical Association stated that African Americans are more likely to receive treatment when an AIDS-related infection requires hospitalization, and that significant numbers of African Americans are diagnosed with AIDS within one month of their death. In both rural and urban areas, Title III providers are critical to efforts to increase the early diagnosis and treatment of HIV within the African-American community.
- Based on 1996 data, Title III grantees are targeting high risk populations, such as: the incarcerated population, homeless persons, runaway youth, injecting drug users (IDUs), migrants, and women and children.

Communities in Need – Unfunded Grants for Underserved Areas

For FY 2000, the CAEAR Coalition seeks an increase of $11 million for unfunded grants to underserved communities.

- The federal government has already approved over $11 million in grants to 28 qualified Title III applicants, but cannot fund these applications due to a lack of appropriations.
- These qualified, but unfunded, applicants are located in rural and underserved urban areas. A total of 23% of Title III programs report being the only HIV medical outpatient program in their area.
- Approximately 50% of all currently funded Title III providers are located in rural areas.

Increasing Cost of Social Services

For FY 2000, the CAEAR Coalition seeks an increase of $7 million for the increasing costs of providing social support services.

- Title III grantees reported to the Health Resources and Services Administration (HRSA) that over $5 million was needed but not available for providing case management services to patients in 1996. In part, this was reflected in fewer clients being able to receive case management service in 1996 than in 1995.
- Title III grantees reported to HRSA that the costs of providing case management services increased by 55% per patient between 1995 and 1996. In part, this can be attributed to the following:
  - an emerging model of case management that stresses adherence to complex drug regimens;
  - a changing welfare and health care environment, requiring more time spent with patients on issues of benefits and entitlements;
  - changing health status of some patients who are considering entering the work force; and
  - housing needs for many Title III patients.

Complete citations of data sources are available upon request.

For further information, contact the CAEAR Coalition,
1413 K Street, NW, Suite 700, Washington, D.C. 20005, 202.789.3565, fax 202.789.4277; or
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CAEAR
CITIES ADVOCATING EMERGENCY AIDS RELIEF

October 16, 1998

BUDGET - FY2000 - NORA/Community

The Honorable William J. Clinton
President of the United States
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear Mr. President:

Cities Advocating Emergency AIDS Relief (CAEAR) is a national grassroots coalition advocating on behalf of people living with HIV disease who depend on Title I and Title III of the Ryan White CARE Act for health care and support services. We include members of Title I planning councils, people living with HIV/AIDS, community-based AIDS service organizations, providers of HIV health care, CARE Act grantees and consortia. We are civic and business leaders, lesbians and gay men, members of religious organizations, government representatives, local public health officials, drug treatment and mental health providers, and representatives from diverse communities of color.

We write to you today to ask that you request FY 2000 budget increases for all CARE Act programs, and in particular, we strongly urge you to include in your FY 2000 budget a request to Congress for $620 million in funding for Title I of the CARE Act and $131 million in funding for Title III of the CARE Act.

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Both the cost and the complexity of the care provided by Title I and Title III programs is increasing. New therapies have placed significant pressure on Title I and Title III communities to ensure that access to these drugs is available and continuous. These new therapies cannot be provided outside the context of overall primary care. Patients need a coordinated medical team that includes higher levels of expertise among nurses, pharmacists, mid-level practitioners and case managers. Care teams must also include ongoing education about adherence to combination drug regimens. Failure to take these medications as prescribed runs the risk of rapid development of resistant viral strains.

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The CAEAR Coalition is seeking an increase of $48 million for Title I and an increase of $12 million for Title III to address the increasing cost of HIV care. The Coalition is seeking an additional increase of $7 million for Title III specifically to meet the increasing cost of providing HIV social services.

Approximately two-thirds of Title I and Title III clients are people of color. However, their utilization patterns of medical care and treatments continue to lag significantly behind their representation in local epidemics. Communities of color experience cultural and environmental barriers to full access to HIV health services. Many people of color living with HIV are burdened by histories of other sexually transmitted diseases as well as substance abuse, mental illness, homelessness and tuberculosis. The combination of these factors often results in difficulties in

accessing health care and support services. The need is expanding for outreach to HIV-infected people of color to ensure they are linked into the health care system as early as possible. Delayed access to care perpetuates the disparities in health outcomes and the rate of reduction in AIDS mortality rates. To address the disparities in outcomes, access and in the utilization of care by people of color, the CAEAR Coalition is requesting an increase of $13 million for Title I and an increase of $10 million for Title III.

The AIDS epidemic has produced dangerous strains on our nation's public health systems. Hospitals have long reported significant losses in caring for AIDS and HIV patients. Despite the recent reductions in hospitalization days and length of stay, the average hospital reports losses exceeding $2,000 per patient per year. As the burdens mount, responding to the needs of the AIDS epidemic grows more difficult and imperils our ability to meet all the other health needs in our communities. Heavily reliant upon funding for all titles of the CARE Act, our communities request that your budget include adequate funds for all titles of the CARE Act, as well as other federal AIDS efforts in prevention, housing and research.

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With Title I and Title III funds, we can save money as well as maintain the health and improve the quality of life for people with HIV/AIDS, but we need your help to do it. Please give people living with HIV/AIDS, their caregivers, family, friends and communities your continued support.

Sincerely,

Matthew McClain
Philadelphia, Pennsylvania
Chair, CAEAR Coalition

Suzi Rodriguez
Los Angeles, California
Vice Chair

Marc Haupert
Los Angeles, California
Treasurer

Heidi Nelson
Chicago, Illinois
Title III Representative

Tracy Fischman
Chicago, Illinois
Title III Representative

Al Ballesteros
Los Angeles, California
Southwestern Regional Representative

Pat Bass
Philadelphia, Pennsylvania
Mid-Atlantic Regional Representative

Jacque Muther
Atlanta, Georgia
Southern Regional Representative

Dr. A. Gene Copello
Jacksonville, Florida
At-Large

Daryl Flynn
Los Angeles, California
At-Large

Harold Cox
Boston, Massachusetts
At-Large

Sue Geissler
Denver, Colorado
At-Large

Ernest Hopkins
San Francisco, California
At-Large