



# Southern AIDS Coalition

## 2006 Ryan White Policy Statement

### CONGRESS MUST

- Reauthorize the Ryan White Comprehensive AIDS Resources Emergency (C.A.R.E.) Act.
- Appropriate a minimum of \$35 million through Title II State Emerging Communities for Care and \$60 million through Title II AIDS Drug Assistance Programs (ADAP) to bring parity of funding across the country.
- Hold harmless at current funding levels all C.A.R.E. Act funded programs—only possible with additional appropriations.
- Use living AIDS cases for distribution of funds.
- Lower to estimated 1,500 living AIDS cases MSA/MD/EMA jurisdictions to be eligible for Title I funds.
- Assure a formal plan be established and action be taken to ensure that HIV/AIDS care becomes a core component of health services provided by 330 clinics / community health centers and other Federally Qualified Health Centers.
- Commit to an equal level of distribution of C.A.R.E. Act funds across the country to every HIV-positive person.

### C.A.R.E. Act Needs Changes to Reach All

The Southern AIDS Coalition believes that all persons living with HIV/AIDS across the United States, regardless of their geographic locations, must have access to 1) appropriately trained, HIV-specific primary medical care providers; 2) services necessary to sustain medical care; and 3) medication formularies consistent with United States Public Health Service guidelines. These goals are consistent with the vision of a moral and compassionate society and contribute to the prolongation/improvement of people's lives, facilitate their positive contributions to family and society, and help to reduce the further spread of this pandemic.

The intent of the Southern AIDS Coalition is to cause no harm to any existing system of care. Any significant change in the distribution of resources—should changes be necessary to accomplish the agreed upon priorities—should be implemented over time to minimize negative impact (should any occur) and maximize the equitable distribution of Ryan White Funds.

The Southern AIDS Coalition (SAC) includes representation from 14 Southern States and the District of Columbia. SAC is comprised of grassroots advocates, government agencies, persons living with HIV disease, and other vested partners from across the country. The burgeoning SAC membership struggles with the HIV/AIDS epidemic in an atmosphere of increasing cases and shrinking resources, in part due to the Act's structure and in part due to the existing formula used to distribute Ryan White funds.

There are 19 states without Eligible Metropolitan Areas (EMAs) that do not, therefore, receive any Title I funds. When one considers all Ryan White funding (excluding Emerging Communities and Special Projects of National Significance (SPNS)) that is distributed across the nation by the Health Resources and Services Administration (HRSA) using a combination of the Center for Disease Control and Prevention's estimated

living AIDS cases as well as some competitive processes, 30 states fall below "equity" in per capita overall C.A.R.E. Act funding. A significant proportion of these states are in the Southern region and the Plains states. It is no coincidence that these are also the states with waiting lists for the AIDS Drug Assistance Programs (ADAP), insufficient formularies, and an absence of services necessary to enable/improve parity of care across the country.

SAC requests that an annual distribution of at least \$35 million be directed to increase Title II base funding to states that receive less than the national average per AIDS case. Those states that qualify would receive a portion of this funding based on the estimated persons living with AIDS. Specifically, for states without Title I EMAs, the total number of living AIDS cases would be used, and in those states with a Title I EMA, only living AIDS cases outside the Title I EMA would be considered if they represent more than 50% of the state's total. The epidemic has reached regions of the country outside of major urban areas. These areas are struggling to provide basic treatment and care; they are in desperate need of federal attention to adjust the funding approach/formulas to ensure parity of federal funding across the U.S.

In contrast to the epidemic's initial phases, the less urban regions are struggling to provide basic treatment and care; they are in desperate need of increased parity in federal funding to match more closely the needs of their HIV-positive citizens. To that end, more needs could be met with a shift in Title I eligibility. **The use of estimated living AIDS cases with a threshold of 1,500 cases to qualify for Title I level funding is critical to ensure access to care and treatment for all who live with HIV disease.**

## REAUTHORIZE THE RYAN WHITE C.A.R.E. ACT

The Southern AIDS Coalition asks Congress to enact these recommendations in order to achieve parity of access to federal Ryan White C.A.R.E. Act Funds.

### Distribution

We support the use of living HIV and living AIDS case numbers in the distribution formula for Ryan White funds beginning 2007 according to the Centers for Disease Control and Prevention. Funds should follow the epidemic.

### Three year awards

Adopt a three-year funding period for all formula and supplemental awards (Title I, Title II, Title IV, Dental, and AIDS Education Training Centers). Annual performance reports will indicate whether adjustments to funding levels from year to year are necessary if a change in living and newly reported HIV and AIDS cases warrants. A hold harmless/protection period must be established within the C.A.R.E. Act to limit significant fluctuations from year to year.

### Title I eligibility change

Lower the Title I eligibility to 1,500 living AIDS cases in EMA/MSA/MD areas with 500,000 persons or more. In fiscal year 2007, base Title I eligibility on living HIV and living AIDS cases at a threshold determined to be equivalent to the 1,500 living AIDS case threshold. This shift will increase the number of funds coming to the South and other regions of the Country.

**This gravely needed program has helped hundreds of thousands; we must reauthorize the Ryan White C.A.R.E. Act to ensure Care and Treatment to the 900,000 who live with this disease.**

### Emerging Communities

Revise the Emerging Communities component of Title II to 1) expand the stability, 2) level out the funding streams, and 3) allow flexibility to address local needs within states. Existing Emerging Communities have experienced great fluctuations from year to year using the current formula with the Tier I and Tier II approach. **SAC requests that new language and funding be directed to increases in the Title II base funds for states that receive less than the national average per living AIDS case of Ryan White funds. The Emerging Communities mechanism is the recommended approach for this increase.** Eligible states are 1) those states with no Title I funds or 2) states with 50% or more of the total living AIDS cases outside of the Title I area. The appropriated funds will go to the eligible states equal to the state's percentage of living AIDS cases. Once a region becomes eligible it will always receive Emerging Communities funds distributed in the same manner. The minimum amount of appropriations required will bring parity state by state through the revised Emerging Communities programs that will fund the

states directly.

### AIDS Drug Assistance Program

Ensure that all individuals in need of medications living below 300% of the federal poverty guidelines receive formularies consistent with Public Health Service guidelines to include Highly Active Anti-Retroviral Therapy (HAART) and Opportunistic Infection (OI) medications through the existing AIDS Drug Assistance Programs administered by the states. Should funds be unavailable to meet this principle, then carryover funds from grantees of all titles, which exceed 5% on the most recently submitted Financial Statistics Report (FSR), shall be redirected to compensate for the AIDS Drug Assistance Program shortfalls. Should the carryover funds also not be adequate, additional funds must be identified to meet this fundamental requirement of HIV disease treatment. While SAC is committed to the hold harmless/protection provision for all Ryan White C.A.R.E. Act programs, in order to meet the requirement of 100% access to necessary medications for all who need them, as a last resort Title I grantees in states with waiting lists, eligibility below 300% of federal poverty level, or an incomplete formulary based on Public Health Service recommendations must first ensure availability of treatment dollars. Other funding mechanisms in addition to increased appropriations need to be also considered. Finally, enable all ADAP programs to gain access to the federal ceiling price or a negotiated lower price, if possible, for all medications.

## APPROPRIATE AN INCREASE OF \$95 MILLION

### **\$35 MILLION FY '06 APPROPRIATION TO EMERGING COMMUNITIES**

The Southern AIDS Coalition **urges Congress to ensure parity in federal funding through an increase of \$95 million targeted to improving the availability and accessibility of care in under funded states across the nation for all those living with HIV disease.** Of that amount, \$60 million (or an amount to meet the goal of 100% coverage) should be devoted to the AIDS Drug Assistance Programs and \$35 million devoted to increasing Title II base awards of states without Title I grantees or with more than

50% of their living AIDS cases residing outside the designated Title I area.

### **AT LEAST \$60 MILLION FY '06 APPROPRIATION TO AIDS DRUG ASSISTANCE PROGRAMS**

Target at least \$60 million to the states in need to ensure access to 100% of those living with HIV at or below 300% of the federal poverty level in compliance with Public Health Service guidelines to Highly Active Anti-Retroviral Therapy (HAART), and access to medications that prevent and treat Opportunistic Infections. The AIDS Drug Assistance Programs have resulted

in multiple waiting lists across the nation. The President authorized a one-time \$20 million appropriation for a moment in time waiting list reduction. A more permanent solution must be achieved, however, for fiscal year 2006; **Congress must commit at least \$60 million to target states that a) have waiting lists for medications; b) are not able to meet the 300% federal poverty level eligibility criteria; and c) do not have formulary offerings based on PHS guidelines, HAART, and OIs.**

**This country must allow life sustaining care and treatment to be distributed based on need and geography.**

Two financing proposals to focus resources on states in need: 1) ADAP Supplemental — at least \$60 million 2) Title II Base Emerging Communities supplemental grants—\$35 million.

### **AIDS Drug Assistance Programs**

SAC requests a distribution of at least \$60 million annually in new funding to states nationwide (including territories) with the greatest needs throughout the five-year authorization period. Priorities should include states with ADAP waiting lists, eligibility and/or formulary restrictions, and factors that may prohibit Highly Active Anti-Retroviral Therapy (HAART)-based treatment and provision of Opportunistic Infection (OI) medications to all persons living with HIV in this country who are in need.

### **Emerging States Funded for Care**

SAC requests an annual distribution of \$35 million in new Title II base funding to states that contain Emerging Communities with distribution of funding based on estimated persons living with AIDS. For states with Title I EMAs, the numbers used would comprise those residing outside the EMAs. The epidemic has reached small, rural, underserved areas of the country. These areas are in desperate need of federal attention to adjust the funding approach/formulas to ensure parity of federal funding across the U.S.

# Poverty & Access to Care in the South

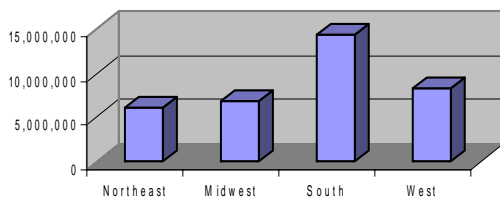
The South is the only region in the United States with a poverty rate increase between 2002 and 2003—to 18% of all Southerners. Sadly, the South also has the highest regional rates of poverty and unemployment.

Estimates from the Centers for Disease Control and Prevention indicate at least 20% (50,000) of those known to be living with HIV disease in the southern region are not in care.

**Three impediments are critical to care accessibility:** 1) **geography**—the transportation to available systems is sometimes impossible; 2) **service availability** shortages—care is unavailable in many locations; and 3) **financial**—systems are overtaxed due to inadequate funding across the country.

**The South and other regions suffering shortages deserve equitable shares of the federal funding that is made available to prevent, care for, and house those living with HIV disease.**

U.S. 2003 Poverty Numbers of People



State	Population	Living with AIDS	Living with HIV	TOTAL Living with HIV or AIDS
Alabama	4,500,752	3,940	5,896	9,836
Arkansas	2,725,714	2,067	2,294	4,361
District of Columbia (3)	563,384	8,848	15,485	24,333
Florida	17,019,068	43,223	32,449	75,672
Georgia (3)	8,684,715	14,023	24,540	38,563
Kentucky (3)	4,117,827	2,359	4,128	6,487
Louisiana	4,496,334	7,592	7,773	15,365
Mississippi	2,881,281	2,875	4,375	7,250
North Carolina	8,407,248	6,545	11,204	17,749
Oklahoma	3,511,532	2,633	2,085	4,718
South Carolina	4,147,152	6,379	6,970	13,349
Tennessee	5,841,748	5,817	6,678	12,495
Texas	22,118,509	21,125	30,043	51,168
Virginia	7,386,330	9,242	7,735	16,977
West Virginia	1,810,354	645	690	1,335
<b>Total</b>	<b>98,211,948</b>	<b>137,313</b>	<b>162,345</b>	<b>299,658</b>

**34% of US Population ♦ 41% of US Living with HIV/AIDS Population**

## Disproportionate Disease for Persons of Color

- **Women of color in the South are 26 times more likely to be positive than white females.**
- **Blacks comprise 12.1% of the U.S. population. The CDC indicates 47% of those living with HIV/AIDS at the end of 2003 are Black, non-Hispanic.**
- **More than 50% of the new infections in 2003 were in African—Americans.**
- **Of over 525,000 deaths, 56% (more than 293,000) have occurred in people of color.**
- **The South has lost more people to AIDS than any other region in the Country. More than 200,000 Southerners have died.**

**The South has 34% of the nation's population and yet accounts for 41% of the living AIDS cases. These are the individuals who need a higher level of care but are provided fewer federal resources because of the existing method of distribution.**



Collaborative Solutions hosts the Southern AIDS Coalition. Please visit us at

[www.southernaidscoalition.org](http://www.southernaidscoalition.org)

### Resources

- *Institutes of Medicine "Measuring What Matters: Allocation, Planning and Quality Assessment for the Ryan White CARE Act."*
- *Population data from the U.S. Census Bureau*
- *The living with AIDS cases are from a CDC supplementary report and covers through 12/31/03*
- *(3) The cases living with HIV are all from the same CDC report except for District of Columbia, Georgia, and Kentucky. Those numbers are derived from the average of 175% more people living with HIV than AIDS at the end of 2003. This percentage was used to calculate the estimated living HIV cases at the end of 2003.*