

Spirits

Lifting as we climb

Volume I, Issue V

December 1995

Dear Reader,

It often feels as if the National Women & HIV/AIDS Project has been a part of my life forever. But NWAP has been in existence for just over two years. While many have criticized us for not being more than we are, at this point we have done a lot with a little.

We incorporated in August of 1993, with little more than the desire to make a difference. NWAP aims to give women, regardless of age, race, sexual orientation, or region of the country access to the prevention education, treatment, and public policy information that will allow them to make informed choices in their lives as both women and women living with HIV and AIDS. NWAP cannot and will not be the sole voice of women living with HIV and AIDS. If I have learned nothing else in the past two and a half years, I have learned that while many will tell you they know exactly what women living with HIV/AIDS want, such knowledge is impossible. Women living with HIV and AIDS are as diverse as any other population in this country and so are their opinions, needs, and choices, all of which must be respected even when they differ for your opinion or mine.

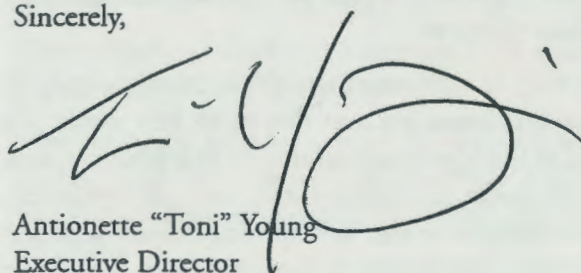
I have tried to keep this lesson in the foreground of this organization's development. In order to succeed in keeping NWAP alive, finding a cure, or changing national and local opinion and policy, we must become far more outreaching, far more inclusive, and far less opinionated. These things are difficult to achieve, at best.

It has been speculated that NWAP is financially and/or philosophically run by a large white feminist institution or is a front for a gay male dominated project. It is neither. It is a project that operates on a shoestring budget from week to week and seeks the support of those who want to support women living with HIV/AIDS regardless of race, class, or sexual orientation.

NWAP, in its short lifetime, has accomplished a few things of which I am very proud, including but not limited to the convening of the 1994 National Women & HIV/AIDS Summit, production of the National Women & HIV/AIDS Agenda, and getting this newsletter out with regularity. These are not projects for which we have grants; they are what was needed.

We are a staff of two, plus many volunteers, including those who organize and layout this newsletter. We do this not for glory or money but because we want to make a difference. We want to do something without the smoke and mirrors, without saying we are larger than we are, but just to do it in a way that gets and keeps women involved and makes a difference in the lives of women. Regardless of your race or gender we need and want your input. It will take more resources to keep NWAP open. Whether that be time, ideas, or a prayer every now and then, we need your support.

Sincerely,



Antionette "Toni" Young
Executive Director

**1996 National Women & HIV/AIDS
Summit postponed from January of
1996 to October of 1996.
(See page 2.)**

BUILDING BRIDGES for Families

If you are a woman living with HIV who has a child or are interested in helping families whose children will be orphaned by HIV/AIDS, we need your input and support!!

Building Bridges is a project of NWAP that responds to the future planning needs of families affected by HIV/AIDS. Our ever-growing network of parents living with HIV/AIDS, advocates, and service providers share information, support, and program/policy models to better address the needs of these families. We want to PROACTIVELY address these issues before the numbers of orphaned children rise out of control, so that mothers can feel assured that they have found safe, stable, supportive homes for their children. We are trying to set up programs that will work with families before the parents die to set up custody plans for their children and to ensure that the parents, children, and future guardians all have access to necessary medical, mental health, and social services. To date, California, Connecticut, Florida, Illinois, Kentucky, Maryland, Massachusetts, New Jersey, New York and North Carolina all have legislation that allows for this kind of prior custody planning. Arizona, District of Columbia, Indiana, Georgia, Pennsylvania, Puerto Rico, Tennessee, Virginia and Wyoming are all working on similar legislation. These joint or standby guardianship provisions allow terminally ill parents to name another individual to act as guardian of their children upon the parent's hospitalization or death. These plans can be made ahead of time to ensure that a parent's wishes are upheld regarding the care of their children.

We are trying to raise awareness about prior planning so that these provisions are available in all fifty states. We also want to share program models so that effective, supportive programs accompany this sort of legislation. Finally, we want to be able to help with training legal service providers, social service providers, and families so that all parties understand how to work their way through the maze of prior planning options.

If you are a woman living with HIV/AIDS who is trying to plan for your children, and you don't know how to access services, we can try to find those contacts for you. If you are a woman who has been able to access services, we want your input to know what is most and least helpful as you move through this process. If you are a legal or social service provider trying to implement a permanen-

cy planning program in your area, and we don't know about you, please contact us and let us know what you are doing. We can also put you in touch with other programs and providers around the country who may be able to assist you in your efforts. If you need help with introducing legislation, we can share other states' legislation as models.

But we need your help, too! Share information about this project with anyone you know who might be interested so we can continue to expand our network. If you live in the Washington D.C. area and would like to volunteer your time to these efforts, please call. We are still seeking funding and support to truly get this project off the ground. With your help, we can and will bring these issues into national awareness.

For more information, contact Kristin Neil, Building Bridges Project Director at (202) 547-1155 or write c/o NWAP. Beginning with the next issue of *Spirits*, there will be a regular section dedicated to issues of permanency planning and the Building Bridges Project.

CDC cryptosporidiosis "voice-fax"

Scott Damon, Health Communication Specialist for the National Center for Infectious Diseases, recently announced that the Centers for Disease Control (CDC) now has a "voice-fax" telephone system for cryptosporidiosis. Callers to this "Cryptosporidiosis Information Line" can listen to recorded messages on cryptosporidiosis and order printed materials, designed for different audiences, by fax. One of the items available is a multi-page informational fact sheet designed specifically for persons who are HIV positive or who have AIDS. The information line number is (404) 330-1242. Many of the same materials available from the information line are also available at the National Center for Infectious Diseases Internet Home Page on the World Wide Web, at <http://www.cdc.gov/ncidod/diseases/crypto/crypto.htm>.

1996 Summit Postponed

The Second Annual National Women & HIV/AIDS Summit which was scheduled for January of 1996 has been postponed until October of 1996 due to a lack of financial commitment. We are still trying to confirm the new date. Watch this space for more updates. Please continue to submit your workshop requests and registration information.

Volunteers needed for study of HIV viral load test

NIAID News

A new multicenter study will determine if monitoring levels of HIV, the virus that causes AIDS, in a person's blood can keep patients healthier longer by helping doctors make better treatment decisions. The study, sponsored by the National Institute of Allergy and Infectious Diseases (NIAID), is recruiting 1100 HIV-infected people through the NIAID-supported Terry Beinr Community Programs for Clinical Research on AIDS (CPCRA), a community-based clinical trials network.

CPCRA study 036 is comparing two strategies for deciding when to change anti-HIV therapy: 1) current clinical practice alone (monitoring the development of or changes in HIV symptoms as well as blood levels of CD4+ T cells, immune cells destroyed by HIV) versus 2) current clinical practice plus periodic tests measuring the amount of HIV, or viral load, in a given amount of blood.

Although doctors commonly change a patient's anti-retroviral therapy when drug efficacy appears to wane, they need better tools for deciding when such changes might be most beneficial. A new technology that detects blood levels of HIV RNA, the genetic material of HIV, has been suggested as a promising way for clinicians to both gauge the effectiveness of therapy and predict when the disease might get worse.

"While many people believe that changes in the level of HIV RNA are good indicators of drug effectiveness, this has never been proven. This study will determine whether use of this expensive technology makes a difference in the quality of a patient's life," says Jack Killen, MD, director of NIAID's Division of AIDS. It is not known, for example, if keeping HIV burden at a minimum with available therapies will have any clinical benefit, or if switching treatments more frequently will result in drug choices being exhausted too quickly.

The CPCRA study team has chosen to use the branched DNA (bDNA) assay for HIV-1, one of several new research tests that measure HIV viral load. The assay yields reproducible results and is relatively simple to perform. Volunteers in CPCRA 036 will be divided at random into two groups of 550 each — a current clinical practice (CCP) arm and an HIV RNA arm. Those in the CCP arm will be taken care of according to current clin-

ical practice. Those in the HIV RNA arm will have bDNA assays performed at least every four months throughout the study, and clinicians will use the results of these tests in addition to current clinical practice to manage the care of these patients. CPCRA 036 does not dictate the use of specific drugs or clinical strategies. Decisions about preventive and therapeutic drug regimens will be decided by the study volunteers in consultation with their doctors.

To be eligible for CPCRA 036, a person must be HIV-infected and in reasonably good health, 13 years of age or older, have a CD4+ T cell count of 300 or fewer cells per cubic millimeter of blood 16 weeks prior to randomization, and receive their care from a participating CPCRA site.

To obtain a list of CPCRA sites expected to participate in the study, as well as contact telephone numbers at those sites, call the AIDS Clinical Trials Information Service at 1-800-TRIALS-A (1-800-874-2572).

Advertising Rates For Spirits

Size	Commercial	Non-Profit
Full Page (7.5 x 10)	\$750	\$500
1/2 Page (3.625 x 10 or 7.5 x 5)	\$360	\$240
1/4 Page (3.625 x 5 or 7.5 x 2.5)	\$190	\$150
Business Card	\$90	\$60

Spirits is produced 7 times a year and has a national circulation of approximately 3,500.

Camera-ready artwork should be shipped with payment in full. Artwork submitted without full payment will be billed an additional 15% administrative fee.

Calendar Listings

Calendar listings are free to all. Please include the following information:

- Event Title
- Description of Event
- Day, Date, Time, and Location of Event
- Event Cost
- Name of Contact Person

Thalidomide effective treatment for AIDS-related mouth ulcers

NIAID News

Thalidomide effectively and safely heals severe mouth ulcers (also called oral aphthous ulcers) in persons with HIV infection, according to an interim analysis of data from a placebo-controlled study supported by the National Institute of Allergy and Infectious Diseases (NIAID).

The study (ACTG 251) compares the effectiveness and safety of thalidomide with placebo for treating patients with severe oral and esophageal ulcers. In the second or maintenance phase of the study, doctors are evaluating thalidomide's ability to prevent recurrences of ulcers in the mouth or the esophagus. As a result of the finding of the interim analysis, current and newly enrolled study participants with oral ulcers will all receive open-label thalidomide rather than being randomized to receive either placebo or drug. Patients with esophageal ulcers will continue to be randomized. (The effectiveness of thalidomide for patients with ulcers in the esophagus could not be evaluated because of limited patient enrollment.)

"Thalidomide is the first treatment shown in a rigorous scientific study to heal these ulcers. As the study continues, we anticipate additional valuable information about the drug's effectiveness and long-term toxicity" said Anthony S. Fauci, MD, director of NIAID. The Ad Hoc Interim Review Committee found that the ulcers had healed in 14 of 23 patients receiving thalidomide compared with only one out of 22 patients receiving placebo. The committee also looked at the safety data available for the first 73 patients enrolled in either the mouth ulcer or esophageal ulcer part of the trial and found no significant differences in severe side effects that could be attributable to either thalidomide or placebo.

According to study chair Jeffrey M. Jacobson, MD, ACTG 251 is continuing to enroll HIV-infected men and women at sites across the U.S. Study plans call for 164 participants. Thalidomide is known to cause malformations in infants born to women taking the drug, and women of child-bearing age who participate in ACTG 251 are fully informed about this risk. For more information about this and other AIDS clinical trials, please call the AIDS Clinical Trials Information Service at 1-800-TRIALS-A (1-800-874-2572).

The Common Cents Fund for Women

NWAP, with the support of NationsBank®, announces the start of **The Common Cents Fund**. With AIDS funding dollars becoming more difficult to obtain, it is important that we find new ways to support NWAP programs and keep the doors open. This effort is one in which not only you but everyone you know can support a grassroots organization through a true grassroots effort.

We are asking individuals throughout the U.S. to help in this effort, and we hope it, like other grassroots campaigns, will grow. NWAP has limited resources and needs the help of partners like NationsBank® and you in order to survive. NationsBank® has agreed to act as a collection site for the change you collect. As many of you may know, most banks will not accept change that is not rolled and wrapped. NationsBank® has agreed to make an exception for participants in **The Common Cents Fund** effort. In addition to donating your own change, here are other ideas that will help get the fund started:

- Explain the project to everyone you know.
- Place a jar in your office, home, or shop along with information on NWAP and ask individuals to bring in change for the jar.
- Put an advertisement in your local paper.

You may want to decorate your can or jar to make it stand out, or offer a prize to the person who collects or brings in the most change. Think of ways to get people involved in this project who otherwise might not contribute to NWAP or to other AIDS projects.

Once you have collected the change take it to your local branch of NationsBank® to be counted and have a bank check made out to the National Women & HIV/AIDS Project. If you do not have a branch of NationsBank® in your community, call the bank manager of the largest bank in your area and tell them that you know NationsBank® is participating and ask them to participate as well. You may want to consolidate your donations into two or three trips to the bank to cut down on the work for both you and NationsBank®. If you want to get involved or sponsor **The Common Cents Fund** in your area, please contact Toni Young at NWAP. NWAP is a tax-exempt organization.

Be a supporter of a true grassroots network!

NWAP, I realize how difficult it is to develop a network reflective of the women living with HIV and AIDS and I want to help. Here is my contribution:

- \$15 Women living with HIV or AIDS
- \$25 Supporters
- \$50 Friends
- \$100 Organizations
- \$250 Businesses and Corporations
- \$500 Patrons
- \$1000 Golden Patron
- Here's my gift of \$ _____

No woman living with HIV or AIDS will be denied membership!

- I would like to receive your material in a plain envelope.
- Sign me up for the Women & AIDS Advocacy Corps.

Send this form with your name, address, city, state, and zip (plus phone, fax, and email, if you like) to NWAP • 710 Eye Street, SE • Washington DC 20003.

NWAP is a tax exempt 501(c) 3 organization.

Combination therapy: The next step

The results of two large drug studies — the Delta trial and ACTG 175 — have important implications for the treatment of HIV disease. These studies prove that combination treatment is more effective than monotherapy in slowing disease progression and increasing survival time, especially among individuals with no prior anti-HIV therapy.

These trials were carried out using first generation AIDS drugs (AZT, ddI, ddC) that show only a limited benefit for the treatment of HIV infection. Researchers now believe that combination regimens that include standard treatments plus 3TC and one or more of the new protease inhibitor drugs will produce greater clinical benefits for a more sustained period. Broad patient access to these promising new therapies will create, for the first time, a real possibility for significantly improving the standard of care for HIV disease and for clinicians to begin individualizing treatment for their patients.

For these reasons, it is imperative that the FDA act promptly and decisively in granting accelerated approval to 3TC and saquinavir, and take every action necessary to hasten approval of the protease drugs from Merck and Abbott now in Phase III studies. It is equally important that Roche, Merck and Abbott immediately start studies

of the protease drugs in combination together and with other anti-HIV agents.

Combination regimens are already a part of the therapeutic arsenal for some individuals. The important next step is for the FDA to quickly approve newer, more effective anti-HIV drugs like 3TC and the protease inhibitors for use in 3- and 4-drug combinations that are expected to improve the quality of life and extend survival among people with HIV infection and AIDS.

For more information please contact Ronald Baker, Editor-in-chief, Treatment Publications at 415-487-8065.

NWAP IS NOW ONLINE!

All of you who have access to computer networks can now reach NWAP at:

WomenAIDS@aol.com

Spirits Survey

We want your input so we can adapt *Spirits* to suit your needs! Please fill in the survey below and return it to us at NWAP; 710 Eye Street, SE; Washington, DC, 20003.

1. How often do you read *Spirits*?
1 2 3 4 5
Never Sometimes Always

2. Are the articles informative?
1 2 3 4 5
No Adequate Very

3. Do you share the copy or content of *Spirits* with others?
1 2 3 4 5
Never Sometimes Always

4. What would you like to see more or less of in *Spirits*?

5. Would you write an article for *Spirits*? If yes, either attach it or give us a call to discuss it.

NWAP is putting out a call for new Board members!

We are seeking nominations for individuals who are living with HIV or AIDS, have a background in fundraising and development, and want to be a part of seeing NWAP grow. Please complete the nomination form at right. You may nominate yourself or someone else. You do not have to be HIV positive or female. However, keep in mind, NWAP and its Board of Directors must be majority women and reflective of the HIV/AIDS pandemic in women.

Spirits is underwritten in part through an educational grant from Glaxo Wellcome.

NWAP Board Nomination

Person Being Nominated

Organizational Affiliation if any

Address

City/State/Zip

Why they would be a good board member

Nominated By (your name)

Governor Pataki takes action to save lives: Mothers to know the results of their newborn's HIV test

AIDS Policy Center

Governor George E. Pataki (NY) announced in early October a major policy change that will allow mothers to learn the results of HIV antibody tests performed on newborn infants by the State Health Department.

"This action is about saving lives," said Governor Pataki. "New York has more babies born with HIV than any other state. I am prepared to do all I can consistent with existing laws to ensure that every HIV-infected infant receives the necessary medical treatment."

The Governor's action settles a lawsuit brought against the State by the Association to Benefit Children seeking mandatory testing of newborn infants and disclosure of the test results to mothers. Negotiations to settle the lawsuit were led by Attorney General Dennis C. Vacco, an outspoken advocate for disclosure of newborn HIV test results.

"Every mother has the right to know if her child has been exposed to HIV so that she and her doctor can take steps to protect her child's health," said Attorney General Vacco. "This settlement is not just a victory for the hundreds of babies exposed to HIV in this state, but also a victory for common sense."

The Governor has directed State Health Commissioner Barbara A. DeBuono, MD, to develop regulations that will mandate prenatal HIV counseling and provide a mechanism for mothers to obtain their infants' HIV test results. The regulations will:

- Allow each mother to indicate on a consent form whether she wants to be informed of her infant's HIV antibody test result.
- Require the Health Department's Wadsworth Laboratory to send an infant's test result requested by the mother to her physician, who will in turn notify the infant's mother.
- Require all prenatal care providers subject to Health Department jurisdiction to counsel pregnant women about the risk of mother-to-child transmission of HIV and encourage all pregnant women to voluntarily be tested.
- Require hospitals to inform new mothers at the time of delivery that blood samples from their newborns

are tested for HIV antibodies by the State Health Department.

- Require hospitals to arrange for necessary follow-up testing and referral to care for the mother and child if the infant's test result is positive.

The State Health Department has been testing anonymous newborn blood samples for HIV antibodies since late 1987, as a means of monitoring the rate of HIV infection among child-bearing women. The test results are not given to mothers or physicians since there is no identifying information on the sample when the test is done currently. The testing is anonymous to comply with the State's HIV Confidentiality Law, which prohibits HIV testing of any individual without written consent.

"The proposed new State regulation is consistent with the HIV Confidentiality Law because the mother would sign a consent form to obtain the child's HIV test result," said Governor Pataki. "Any mother who does not want her child's test result may indicate her refusal on the consent form."

When a newborn infant tests positive for HIV antibodies it means that the mother is infected, because newborns have antibodies from their mother's blood at birth. Further tests are necessary to determine if the baby is infected. About 20 to 25 percent of infected mothers transmit the virus to their babies.

Physicians can now significantly reduce the risk that an HIV-infected mother will transmit the virus to her child if it is known early in pregnancy that the mother is infected. The antiviral drug AZT taken during pregnancy has been shown to reduce the risk of HIV transmission from a mother to a child by as much as two-thirds — from 25 percent to 8 percent.

"This is the first really good news we have had in the 15-year history of the AIDS epidemic," Commissioner DeBuono said. "I firmly believe that if pregnant women are given this important information, virtually every woman will want to take the test to protect her child."

Prenatal care settings that would be required to counsel pregnant women include hospitals, clinics, and managed care organizations. The mandate would not apply to physicians in private practice, although the Health Department has appealed to all physicians to make HIV counseling and voluntary testing a routine part of prenatal care.

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Women's Network for Change — Action Alerts!!

Proposals to cut the Earned Income Tax Credit will hurt working poor

The Earned Income Tax Credit (EITC) is a refundable tax credit available to the working poor. Since its creation, EITC has been supported by both Democrats and Republicans. It was hailed by President Reagan as "the best antipoverty, the best pro-family, the best job creation measure to come out of Congress." Last year the EITC helped more than 2 million families stay out of poverty, yet the Senate is proposing to cut the EITC by \$43.2 billion, and the House by \$23.3 billion to pay for tax cuts for higher income Americans.

- Working poor families will pay for tax cuts for higher income Americans. Families struggling to remain economically self-sufficient with incomes between \$11,630 and \$25,300 will sustain tax increases or see their incomes shrink, while those with incomes over \$200,000 will see big gains under the tax proposals. Under the Senate proposal, almost 20% of the \$245 billion in tax cuts will be financed by cuts in the EITC.
- Cuts in the EITC will disproportionately affect women who represent nearly 75% of all EITC recipients. Almost half of all families headed by single mothers are poor, partially because women earn on average 70% of what men earn. Women who have left welfare and can now support their families will be hurt by the cuts in the EITC which helps them pay for food, clothing, transportation, and shelter, and keeps them from going back on welfare.
- The Senate tax proposal could increase the number of families needing public assistance by cutting a tax benefit that strengthens incentives to work and has helped keep working poor families off welfare. The cuts in the EITC will increase taxes for as many as 17 million working poor families, forcing many who cannot support their families to turn to welfare.

Welfare reform leaves women without job training or child care

Since 1935, Aid to Families with Dependent Children (AFDC) has been the main welfare program that provides basic cash assistance to needy families living below the poverty line. Currently there are 14.1 million people

receiving AFDC, and of those 4.1 million (29 percent) are women and 9.6 million (68 percent) are children. Reviews and studies demonstrate that AFDC must be overhauled. However, any overhaul of a social safety net program of which 97 percent of recipients are women and children must be done carefully, without hurting the children and by realistically moving their mothers from welfare to work.

- The House and Senate welfare reform bills are unrealistic because the bills mandate that welfare recipients work, but do not include the education, job training, or child care necessary to permanently leave welfare for work. Half of the applicants for welfare are re-applicants, many of whom have worked and cannot earn enough money to support their children with their existing skills.
- The House bill penalizes poor children because it denies aid to children born to unmarried teenage mothers, children born to women already receiving welfare, and children whose paternity has not been established. If these policies were in place today, it is estimated that 5-6 million children would lose all support.
- The Senate budget bill would increase taxes on the working poor. Currently, the Earned Income Tax Credit (EITC) decreases taxes for low-income working families and helps millions of low-income working families leave welfare and stay off of welfare. Last year, over 2 million families stayed out of poverty because of the EITC. The Senate bill drastically cuts EITC, increasing taxes for 17 million low-income working families.

Here's what you can do!

Call your Representatives or Senator (202-224-3121) and tell them to oppose welfare reform that goes too far and doesn't give women the skills and child care necessary to leave welfare permanently. Ask them also to oppose cutting the EITC for working poor families.

Copy these alerts and post them in public places, such as day care centers and supermarkets.

Share this information with friends and others in your community.

"Governor Pataki" from page 7

New York State leads the nation in the cumulative number of diagnosed AIDS cases and the number of women and children who have developed AIDS. To date, nearly 92,000 New Yorkers have developed AIDS, 19,000 of whom are women, and 1700 are children who have developed AIDS due to maternal transmission of the virus.

The Health Department data reveal that approximately 1400 HIV-infected women give birth annually in New York State, and 20 to 25 percent of their infants also become infected. This means that about 300 to 350 HIV-infants are born each year in New York.

Regulations proposed by the State Health Department must be published for a public comment period, and adopted by the State Hospital Review and Planning Council before they can take effect. The agreement is subject to court approval.

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Ryan White reauthorization stalled again

HIV Policy Watch, San Francisco AIDS Foundation (SFAF)

The Ryan White CARE Act reauthorization passed the House of Representatives by voice vote on September 18th. The Senate passed its version of reauthorization in July on a 97 to 3 vote. A conference committee of House and Senate members was to meet soon after the House vote to iron out differences between the two bills before a conference report (a unified bill) is sent to both chambers for a final vote and then to the President for signature. The current Ryan White Act expired September 30th.

Unfortunately, despite these great victories in each chamber, both chambers delayed in appointing members to the conference committee. The House has still to appoint its conferees. As a result, the bills remain stalled in conference committee. This is problematic as the Congress is now becoming consumed with the massive task of reconciling the many appropriations bills, tax bills and Medicaid and Medicare overhauls to create a complete FY1996 budget.

The conference committee now appears unlikely to act before early November. At present, this odd gap in authorization for Ryan White will not cause any disruption in funding or operation of Ryan White programs across the nation as funding for the programs is occurring through the Continuing Resolution that runs until November 13th. If reauthorization is delayed much longer, however, it could have negative implications for Ryan White programs. These implications are as yet unclear.

As detailed in October's *HIV Policy Watch*, there remain many important differences between the Senate and House bills. Through the CAEAR Coalition (Cities Advocating Emergency AIDS Relief), SFAF continues to work against the horrible provision on mandatory testing of pregnant women and newborns in the House bill; against the nonsensical single appropriations mechanism for Titles I and II; and in favor of a strong hold harmless provision for all current Title I cities.



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