NATIONAL WOMEN & HIV/AIDS PROJECT

Spirits

Lifting as we climb

Volume I, Issue III *June/July 1995*

Dear Reader,

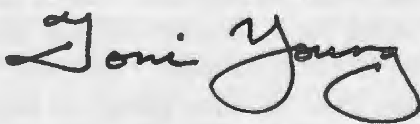
As Eleanor Roosevelt said prior to World War II, "This is no ordinary time." As Congress and others in this nation move toward mandatory HIV testing of women of childbearing age, it is more important than ever that you speak out—write to those at the Center for Disease Control and Prevention and at Health and Human Services and tell them what you think about mandatory testing.

NWAP is here to give voice to women living with HIV/AIDS. However, if you—both women and advocates of women—do not take the time to call and write, others will make decisions about our lives. If you don't already know your representatives in Congress and on the state level, I urge you to take a moment and find out. Write to them and tell them your story. Sign the letter if you can, write anonymously if you don't want them to know who you are.

Now is the time for you to speak out. Many of you have never done this before, but you must find the courage to do so. Laws are changing rapidly and those in positions of power are making them *about* you, not *for* you. If you need help writing a letter, call NWAP or call your local agency.

In this issue of the newsletter you'll find article on the CDC infant HIV survey and on Guardianship. Please read them. We all must plan and prepare for the future.

Sincerely,



Toni Young
Founder and Executive Director

HIV survey of childbearing women draws controversy, is suspended

AIDS Legal Referral Panel, Women's AIDS Network, San Francisco

The HIV Survey in Childbearing Women, the largest source of epidemiological information about HIV infection in women, appears to be the latest casualty in the never-ending fight over mandatory and non-confidential testing.

Facing strong political pressure and legislation that would fundamentally change the study, the Center for Disease Control and Prevention (CDC) announced during a May 11 Congressional hearing on HIV testing issues that the Survey is suspended, effective immediately.

Since the beginning of the epidemic, various legislators and interest groups have called for forced testing, names reporting and other techniques to identify people with HIV infection. In some cases, these attempts have been successful. In California, for example, sex workers and patients whose bodily fluids may have infected a health care worker can be mandatorily tested for HIV and have their test results disclosed without their consent.

And if the current political climate is any indication, the next group to face the prospect of mandatory testing will likely be childbearing women.

Controversy over newborns and perinatal transmission

The drive to test pregnant women and new mothers has sprung primarily from the widely-publicized results of the ACTG 076 study, which found that AZT could reduce the chance of pregnant women transmitting the virus to their fetuses. As soon as the 076 results were published, they were seized upon as a light at the end of the long tunnel of efforts to interrupt the HIV transmission process.

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Largely overlooked were the concerns of women's health and AIDS activists that they study was called off before completion, that it only applied to HIV-positive pregnant women with high T-cell counts and no history of taking AZT, and that the long-term effects of AZT on both women and children were unknown.

Mandatory testing

The 076 results immediately sparked calls to mandatorily test pregnant women and, in some cases, to mandate that pregnant HIV-positive women take AZT. Mandatory testing legislation was introduced—but was eventually either tabled or defeated—in New York, Michigan, Pennsylvania, and Florida.

The problem for proponents of such legislation was that mandatory testing is nearly universally opposed by HIV advocates and public health authorities, including the National Institute of Medicine and the CDC. The CDC draft guidelines for health care providers regarding the 076 study explicitly recommended against mandatory testing on the grounds that it may "result in some women avoiding prenatal care altogether [and] . . . may adversely affect the patient-provider relationship."

The HIV survey in childbearing women

A prime target for 076-inspired legislation was the HIV Survey in Childbearing Women. Since 1988, the CDC has conducted the Survey in conjunction with health departments in 45 states, the District of Columbia, Puerto Rico, and the Virgin Islands. Researchers anonymously test blood specimens from 25-100% of newborns in each region to track the prevalence of HIV infection among childbearing women in those areas. The information is used to target care and services for women.

Because babies carry maternal antibodies, *newborn test results only conclusively indicate the mother's HIV status.* HIV antibody tests *cannot* accurately indicate children's HIV status until they shed their maternal antibodies, usually 18-20 months of age. Although every child born to an HIV-positive mother will initially "test positive," an average of only 20-25% of these children are actually infected.

Because each newborn test in the Survey is performed anonymously and cannot be traced back to an identifiable individual, informed consent is not required and women who participate in the Survey are not necessarily told that it is being done. This is in accord with established federal regulations regarding anonymous statistical studies.

HR1289: The Newborn HIV Notification Act

Following closely on the heels of proposed New York and California State legislation, U.S. Representative Gary Ackerman (D-New York) introduced HR1289, the "Newborn HIV Notification Act," on March 22. This bill would require states to record the infant's name with each tested blood sample and report the maternal antibody status to the child's mother and physician and to foster care authorities when appropriate.

This would change the Survey from an anonymous statistical study into a tool for making individual diagnoses of HIV infection in women. But the bill makes no provision for informing women that the test is being done, counseling them about what the test means, or giving them the opportunity to refuse it. Recognizing that "unblinding" the Survey would result in testing childbearing women without their knowledge or consent, Representative Ackerman has stated, "In an ideal world, the best solution would be to counsel all pregnant women . . .[but] if this were an ideal world, this legislation would not be necessary."

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Social Security and women: what every woman should know

This new booklet is now available at your local Social Security office. The information in this booklet recognizes the changing role of women, especially the increase in the number of women in the nation's workforce. The booklet explains such things as the protection a working woman and her family have if she becomes disabled or dies or when she retires. It also explains what benefits a wife or widow and her children can get on the basis of her husband's work record and how remarriage or divorce affects benefits. Social Security and Women can also be obtained by calling Social Security's toll-free telephone number (800-772-1213) between 7 a.m. and 7 p.m. (EST) on business days. The lines are busiest early in the week and early in the month, so it's best to call at other times.

Caring for our children: Guardianship

Kristin C. H. Neil, Legal Services for Children

Part of caring for your children is planning for their future. While difficult, it allows you a chance to be an active part of that planning and to help ease the transition for your children. It is helpful to begin planning for your children's future as early as possible. There are complicated issues involved in giving over the care of your child to another individual, and these can be easier to deal with while you are still healthy. Making early plans can ensure that your children do not end up in the foster care system or with a parent or relative who you believe would not provide a good home for your children.

Choosing someone to take care of your child when you are no longer able to means looking at your support system and finding someone who you can trust. This can often bring up issues around confidentiality and disclosure of your HIV status to family, friends, and your children. Involving your children in these decisions is an important part of helping your children prepare themselves for the transition after your death and for facing bereavement issues. Developing a support network of people who you trust and who can help you with these decisions is an important part of going through this process. You deserve to be provided with the information to help you make these choices and to be supported in your decisions.

You have many options available to you, and it is important to discuss your unique needs with friends and providers in order to determine which option is best suited to your situation. Naming a guardian in a will is one possibility, but gives you no guarantee that the court will go along with your choice after your death. If another surviving parent or relative makes a claim that is different from your wishes, they may be able to get custody of the child. In an adoption, your child is given a new set of legal parents, and you give up all parental rights. Adoptions require going to court and are a longer, more involved and more expensive procedure. Adoptions are also a permanent option; they cannot easily be changed once carried through. A Guardianship proceeding transfers all of your custody rights (rights to decide where your child will live and go to school, and what kind of medical treatment your child will receive) to a chosen guardian. While you are still legally your child's parent, you no longer have an active role in making decisions regarding your child.

Recently, several states have passed laws that introduce a new aspect to guardianship, called Standby Guardianship. This option allows terminally ill parents to make permanent plans without giving up their legal rights. You may name someone to be the guardian of your child, who "stands by" to take care of your child in the event that you are no longer able to do so. This option makes it possible for a parent to give someone legal authority to take care of her child when she is ill, and then to resume acting as a parent when she is feeling better. In California there is a variation on this law, called Joint Guardianship. In Joint Guardianship the parent shares authority with the chosen guardian, so that both the parent and the guardian make joint decisions for the child from the time of approval of the guardianship. This means it is not necessary to go back to the court to transfer authority from the parent to the guardian. These guardianship options mean you do not have to "give up" your children in order to create permanent plans for their future. Rather, these options allow you to play an active role in the creation of future plans, giving you peace of mind and aiding the transition for your children.

Standby Guardianship currently exists in Florida, Illinois, Maryland, New Jersey, New York, and Pennsylvania, and Joint Guardianship in California. Connecticut, Georgia, Indiana, Massachusetts, and Wyoming are all working on Standby Guardianship legislation. In addition, various groups around the country are discussing a National Standby Guardianship Bill which has been introduced by Congresswoman Carolyn Maloney of New York. To find out more about this process, you may contact Kristin Neil from the Standby Guardianship Working Group at the HOPE Project, Legal Services for Children, 1254 Market Street, 3rd Floor, San Francisco, CA 94102. 415-863-3762. Also available from Legal Services for Children in San Francisco in several languages; "The Guardianship Pamphlet: Legal Guardianship in California, What It Is, How To Do It."

News from the National Institute of Allergy and Infectious Diseases

Dendritic cells: A key to early HIV infection

Patrolling immune system cells called dendritic cells may begin the HIV disease process by carrying the virus from the site of infection to the lymph nodes where other immune cells become infected. "Dendritic cells probably have particular relevance to HIV infection because they are the first immune system cells to arrive at sites of inflammation on mucous membranes, the major site of sexual transmission of HIV," says Dr. Drew Weissman of the HIAID Laboratories. Dendritic cells travel through the body and bind to foreign invaders, especially in external tissues such as the skin and the membranes of the gut, lungs, and reproductive tract. Once the cells encounter an invader, they ferry the foreign substance to lymph nodes to stimulate T cells and initiate an immune response.

Drug-sensitive HIV could make safer AIDS vaccine

Experimental vaccines based on live but weakened or attenuate forms of HIV could be safer thanks to a drug-susceptible HIV clone created by scientists at the NIAID. Although attenuated live-virus vaccines have been licensed for several other diseases, many scientists think that such a vaccine based on HIV, which causes a fatal disease, may be too hazardous. HIV multiplies by inserting its genetic material into that of its hosts' cells, raising concerns that even if crippled so as not to cause disease, HIV could lead to long-term, unanticipated side effects. To bypass this problem, NIAID doctors added to HIV a foreign gene that codes for a protein (thymidine kinase or TK) that can be selectively killed by a drug called ganciclovir. Under laboratory conditions, ganciclovir eliminated cells infected with HIV-TK, suggesting that after it has had a chance to work, an attenuated vaccine based on the HIV-TK clone could similarly be eliminated using ganciclovir.

Chimpanzee vaccine model protects against HIV-1 infection

Chimpanzees inoculated with one HIV-1 strain can resist later infection with a different strain, according to scientists from the National Institutes of Health (NIH). Unlike humans, chimpanzees infected with HIV-1 fail to develop disease. The scientists reasoned that an HIV infection might act like a weakened live-virus vaccine such as the Sabin polio vaccine. Subsequent studies showed that chimpanzees can be protected from a subsequent challenge with HIV-1, provided the animals are first immunized with a potent attenuated live-virus vaccine. Experiments in progress will ascertain how the extent of virus attenuation correlates with resistance to subsequent HIV infection.

Resource list for holistic treatment and information about HIV/AIDS

compiled by River Huston, edited by Stan Heleva, and distributed by the Women's Wellness Fund; April 1995

The third update of this valuable resource list is a way for you to become and remain informed about treatment for HIV/AIDS. Introducing the list, River Huston writes

> Don't look for a magic cure in this information. It is all about supporting and strengthening the immune system as well as healing or alleviating opportunistic infections related to HIV/AIDS. Try one book or subscribe to a newsletter that appeals to you and read it and go from there. I have been gathering information on these kind of therapies for three years. I have found that Traditional Chinese Medicine works best for me at this time. It may work for you, it may not be what you are interested in. If you choose conventional therapies there are ways to balance the toxic side affects. . . . AIDS is a complicated syndrome, it is best to work with a knowledgeable practitioner whether they are a doctor, an herbalist or an acupuncturist, make sure they are well rounded and up to date on what is going on in the field of HIV/AIDS. . . . One last word, be kind and gentle to yourself, the process of living is difficult and HIV makes it that much harder. I have found that HIV has forced me to realize many things about myself; it has been a motivator towards positive change in my life, "a wake up call." This is one of the possibilities of living with HIV. Best of luck.

To obtain the resource list contact the Women's Wellness Fund or River Huston both at 18 N. Main Street, New Hope, PA 18938.

Conferences and Events

AIDS, Medicine, and Miracles
June 1–4, 1995; Omega Institute; Rhinebeck, NY

This is the eight annual AIDS, Medicine and Miracles retreat, a supportive, healing environment for people living with HIV/AIDS, their partners, loved ones, and caregivers. The retreat explores all that holds promised from both western medicine and alternative and complementary therapies. With a strong emphasis on caring for the whole person, sessions are designed to touch the heart and soul. Sessions include treatment issues, intimacy, grief and loss, massage, nutrition, acupuncture, and more. The retreat includes two all-day seminars on Thursday (June 1): Women and AIDS, and Positively Well Institute. Partial scholarships are available to people who are HIV+ and experiencing financial hardship. For more information call 800-875-8770.

Educating About Sexuality
1995 Mid-continent Region Annual Conference of the Society for the Scientific Study of Sexuality
June 1–4, 1995; Holiday Inn Metrodome; Minneapolis, MN

This conference is open to professionals and students interested in the latest developments in human sexuality education in various contexts. For more information contact the Society at 319-895-8407.

3rd National School Health Leadership Conference and Conference on Preventing HIV Infection Among School-Aged Youth
June 12–16, 1995; Westin Peachtree Plaza Hotel; Atlanta, GA

These twin, back-to-back conferences are sponsored by the Centers for Disease Control and Prevention and the U.S. Department of Education.

Facing Our Challenges, Celebrating Our Lives: Lesbian and Gay Health in the 90's
17th National Lesbian and Gay Health Conference and 13th Annual AIDS/HIV Forum
June 17–21, 1995; Minneapolis, MN

Sponsored by the National Gay and Lesbian Health Association and the George Washington University Medical Center, the conference includes both pre-conference institutes and sessions focused on eight educational tracks: AIDS/HIV forum, mental health, strategies for inclusion, research, lesbian and gay health, substance abuse, education and prevention, and violence. For more information call the conference office at 202-994-4285.

National Women and HIV/AIDS Agenda and Survey Results

This publication is the result of the coming together of over 185 women at the National Women and HIV/AIDS Summit sponsored by NWAP in October 1994. Copies are available for $7.50 each from NWAP.

National AIDS Treatment Advocates Forum
October 15–18, 1995; Century Plaza Hotel & Tower; Los Angeles, CA

This is the first annual meeting for treatment advocates and is sponsored by the Research and Treatment Advocacy Department of the National Minority AIDS Council and co-sponsored by the American Foundation for AIDS Research, AIDS Project Los Angeles, Gay Men Health Crisis, Project Inform, and the Treatment Action Group. The goal of the meeting is to build dialogue and coordination among AIDS research and treatment advocacy organizations. For more information contact David Barre at 202-544-1076.

Coming Together, Moving Strong: Mobilizing an Asian Women's Health Movement
November 17–19, 1995; Miyako Hotel; San Francisco, CA

This is the first national Asian women's health conference and the purpose of the conference is to provide information, resources and a venue for mobilizing and engaging Asian women and girls in an Asian women's health movement, and to facilitate dialogue between the Asian American community and policy makers. Workshop topics will include mental health, sexual harassment, reproductive health technologies, aging, alternative medicine, cervical cancer and breast health, environmental and occupational health, HIV/AIDS, nutrition, and an examination of community-based health care delivery. The conference is sponsored by the National Asian Women's Health Organization. For more information call 510-208-3171.

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The arguments

Proponents of HR1289 have argued that the measure is necessary in order to identify children who are HIV-infected to best plan for their medical needs. AIDS and women's health advocates, whoa re nearly universally opposed to the bill, have countered that the bill will not identify HIV-positive children, will do nothing to increase children's access to care, and will provide a disincentive for women to seek care for themselves or their children.

Virge Parks, ACT-UP Golden Gate member and community consultant to Pediatric AIDS Clinical Trials Group charged, "If Congress really wanted to do something about saving babies' lives they would fund focused prevention programs for women and guarantee access to prenatal care. HR1289 is mandatory testing for child-bearing women, and will keep women and their children out of care. To 'save' babies from HIV, we need to prevent infection in women."

Canceling the Survey

Activists had long expected that the administration would cancel the Survey if the Ackerman bill passed. Because it is administered as an anonymous epidemiological study, the linking of names and test results would require that the Survey be largely scrapped and rebuilt from the ground up. But the CDC surprised everyone, including Representative Ackerman, when it announced the administration's decision to suspend the Survey during last week's hearing on HIV testing issues, well before HR1289 was scheduled for a vote.

AIDS and women's health activists reacted angrily to the abrupt announcement, charging that the decision to end the Survey was political cowardice, and that the administration was more interested in avoiding controversy than in researching women and HIV. Eileen Hansen, President of the Women's AIDS Network and Public Policy Director of the AIDS Legal Referral Panel remarked, "Suspending the Survey makes absolutely no public health sense. This decision may blunt Ackerman's current effort, but it also caves in to political pressure from those who would mandate testing and ignores the importance of the Survey. No one disputes the fact that this is one of the best tools for targeting care and services for women. Why cut it now when women are one of the fastest growing populations of people with HIV?"

Back to testing

Not surprisingly, media reports indicate that Representative Ackerman may now pursue efforts to require testing of all pregnant women and newborns. If he is successful, and if the administration decides to permanently cancel the Survey, we will simultaneously begin nonconsensually testing a significant portion of the female population and end our best method for planning care and services for this population.pending. To work against the federal and state "unblinding" bills, contact Eileen Hansen or Rachel Maddow of the Women's AIDS Network at 415-291-5454.

1996 National Women & AIDS Summit; January 17-19 in New Orleans

- ❑ Yes! I want to help get ready for New Orleans.
  - ❑ I/we would like to be co-sponsors of the 1996 Summit.
  - ❑ I can call people in New Orleans to help.
  - ❑ I wouild like to do a workshop.
  - ❑ I will begin working in my local community to find funding for women to attend.
  - ❑ I will send out registration applications when they are available.
  - ❑ I will write and tell you how I can help.

- ❑ No. I cannot participate this year. However, I would like to help support getting a woman to the Summit. Here is my contribution of ______ .

Return to: NWAP; 710 Eye Street SE, Washington, DC; 20003

Project Inform fact sheets and discussion papers

Project Inform (PI), based in San Francisco, is a grassroots organization focusing on the dissemination of information on HIV-related issues and treatments. PI can be reached either through their national treatment information hotline 10am to 4pm (Pacific Time) Monday through Saturday at 1-800-822-7422, or at 1965 Market Street, Suite 220, San Francisco, CA 94103. Below are exerts from two PI publications.

Day One ... After You've Tested Positive: Project Inform Discussion Paper #1

A positive HIV antibody test is scary news to just about anyone. Many people immediately fear it's a death sentence, while others just want to pretend it's all a mistake. Whatever else it is, a positive test result is valuable news that will actually make it possible to save your life. If you didn't learn about it this way, you would have waited for a serious infection to announce the presence of HIV. Either way, you would have found out. But if you had waited for the disease to announce itself, many of your best medical options would already be lost. As crazy as it sounds, learning that you're antibody positive—while still healthy—is a lucky break. At least compared to the alternatives.

Most testing centers also provide counseling to help people handle the news. The real work, however, is up to you. Given the right treatment and the right attitude, HIV infection can be managed like a chronic illness, one which you can survive. Making it so requires some effort on your part. Several things are needed, just to get started:

- Learning more about how HIV works
- Taking additional tests and learning what they mean and what to do about them
- Finding out about your options for intervention
- Making changes in your life to adapt to your new situation

Reading this Discussion Paper is a good first step. It's a little long, but it's worth the time. It's about saving your life.

[The Discussion Paper goes on to cover HIV and the Immune System, Monitoring Immune Health, Intervention Against HIV, and Available Treatments.]

Preventing PCP: Project Inform Fact Sheet

PCP Prophylaxis is the prevention of PCP (pneumocystis carinii pneumonia), a once rare lung infection. Despite the availability of various preventive treatments, PCP remains a leading cause of death resulting from HIV infection. Many doctors treating people at risk of developing PCP are still not prescribing preventive treatments, despite the fact that without prophylaxis over 80% can expect to develop one or more episodes of PCP. A majority of all people with HIV in the U.S. still receive their initial AIDS diagnosis as a result of PCP. Clearly, the best way to handle PCP is to avoid it altogether.

[The Fact Sheet goes on to discuss What Does the Research Show?, What About Side Effects?, Who Should Use PCP Prophylaxis?, and How to Use PCP Prophylaxis.]

Two studies published on AIDS-related infections

New England Journal of Medicine, 3/16/95

Two studies of therapies for AIDS-related infections were completed recently by the AIDS Clinical Trials Group (ACTG) of the National Institute of Allergy and Infectious Diseases.

In patients with advanced HIV infection, three treatments have similar effectiveness in preventing Pneumocystis carinii pneumonia (PCP). Investigators assessed the risks for developing PCP during 36 months of therapy among more than 800 patients with HIV and 200 or fewer CD4+ T cells. The risk for developing PCP was 18 percent among patients taking tremethoprim-sulfamethoxazole (TMP/SMX), 17 percent for those receiving dapsone and 21 percent for those on aerosolized pentamidine therapy. For patients with fewer than 100 CD4+ T cells, therapies that start with TMP/SMX or high does dapsone are superior to treatments beginning with pentamidine.

The second study reported that Fluconazole was more effective than clotrimazole in preventing fungal infections in patients with advanced HIV infection, particularly those with 50 or fewer CD4+ T cells. In a substudy of patients in the previous study, researchers found that fluconazole reduced the frequency of cryptococcal meningitis, esophageal candidiases as well as superficial fungal infections.

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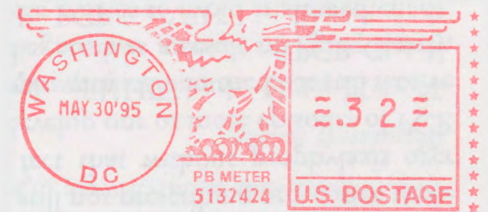

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