

The Quarterly Newsletter of Beyond AID/:

Reversing the HIV Epidemic Through *Sound* Public Health Policy

## Coming Up...

#### Gala Mother's **Day Fundraiser**

...May 14, 2000 "Celebration of Motherhood" to benefit Baby AID/ awareness. Featured performer is Neena Ananda, Indian Classical Dancer. 3 PM at Thousand Oaks Civic Arts Center. Beyond AID/ Annual **Board and General** Meetings

#### ...Late August/ early∫eptember

The board will meet in conjunction with a general meeting at the home of Beyond AID/ President Cary ∫avitch in Ventura, CA. Date TBA.

#### East Coast Chapter Meeting ....Date TBA

All members, friends and associates of Beyond AID/ are welcome to attend; we will hold this meeting in conjunction with or just after an event with Rep. Coburn's office and/or the Independent Women's Forum.

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# February Beyond AID/ Legislative Workshop to Prevent Baby AID/ a /uccess Bill to Prevent Baby AID/ Launched at Beyond AID/ Workshop

At a workshop in Ventura February 19 Ron Hattis, MD and Karen Darnall, legal advisor, went over the legislative language of the proposed bill to prevent babies being infected with HIV at birth. The updated versions of the Baby AID/ bill are posted periodically on the web site at www.beyondaids. org. Corrections and amendments were made. We are requesting universal, routine HIV prenatal



Robert Pacheco, bill sponsor

screening of all pregnant women. This is the suggestion of the National Academy of ∫cience's Institute of Medicine (IOM). Testing would be similar as to what is already done for hepatitis B and syphilis. Any women who refuse HIV testing would do so by signing a

Beyond AID/ legal advisor Karen Darnall discusses strategy with Ron Hattis, MD, Beyond AID/ Vice President.

waiver. However, there would be testing of the newborn in those circumstances.

An HIV epidemiologist from LA County discussed the logistics of prenatal testing, cost and benefit analysis, and comparative situations with other diseases of the newborn.

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## A County that Changed HIV History

eyond AID/ held pivotal meetings in Pasadena and in Ventura, California December 11-13, 1999.

The highlight of the weekend conference was the presentation by Frank Hayes of Pierce/Tacoma, County Washington on how HIV was being reported in that / tate.

His county, under the courageous leadership of Federico Cruz-Uribe, MD, unilaterally mad HIV reportable by name. Washington State was then forced to adopt the names reporting statement, but the AID/ Exceptionalists were able to get policy through that would require the health departments to destroy all records after 100 days, as if the HIV-infected individual is no longer infected or communicable.

Again Dr. Cruz defied the state and has maintained records in order to do partner notification and case follow-up.

∫upporting courageous public health officials is what Beyond AID∕ is all about. ▲



Frank Hayes





Thanks to all of you for the continued effort to make this a safer world.



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## President's Message

Friends and Colleagues,

I wish to thank all of you for attending (in person or in spirit) our December Beyond AID/ meeting. The turnout was very good. Many issues were discussed and the input from new participants was most useful. (/ee article and pictures on page 1).

Two projects Beyond AID/ wants to take on: 1) HIV Partner

Protection Act for California 2) Baby AID/ Bill for California. This will require tremendous work—getting the right legislative authors, public awareness campaign that California still does not report HIV by name to public health departments. Despite over 80,000 Californians who have died of AID/ and another 150,000 that are infected (and who are in trouble and who are communicable).

The realization that there is no requirement to test pregnant women and babies for HIV is still haunting, but a fact of life. The lifetime cost to treat a single baby with AID/ is \$418,000 (Milwaukee study) and they all die. Why are we not making every effort to stop babies from becoming infected in the first place? Those who

### Membership Application

611 Pennsylvania Avenue, JE #1600 Washington, DC 20003-4303 www.beyondaids.org E-mail BeyondAID/inc@aol.com Fax: 703-243-6235

Title

Affiliation

Name

∕treet

∕tate

Country

Apt. No.

E-mail (preferred means of communication)



wish to help on either or both projects, please get back with me (or Ron Hattis MD, email ronhattis@ aol.com).

On a personal note—last month I lost one of my AID/ patients (and friend) to Cryptococcal Meningitis. I had followed him for the past 5 years. Yesterday I saw his partner in the office. I had gotten to know the partner quite well, and had been told

by him that he was HIV-negative and very careful (safe sex and the rest). Unfortunately he had two Kaposi's farcoma (Kf) lesions on his right leg and matted down lymph nodes in his neck. He refused the treatment that did not save his lover. A CD4 count is pending. Pf—ages 34 and 32.

The Beyond AID/ Board and Advisory Council wishes to thank all of you for the continued effort to make this a safer world.

Best regards,

ar Cary / avitch, MD

President, Beyond AID/

- ✓ YE/! I want to join Beyond AID/ for \_\_\_\_\$20\_\_\_\$30\_\_\_\$40\_\_\$50. (✔ one)
- □ I want to help. Please accept my additional donation\* of \_\_\_\_\_.

Add me to your e-mail list only, as a non-voting Associate Member. I am making a voluntary contribution of \_\_\_\_\_\_.

#### Committee interests:

Credit Card No.

] | Telephone

Zip

*J*ignature

### HIV & the Law



# Questions & Answers About HIV

Q: Can I be tested for HIV without my written consent?

A: No. In California, we have specific laws that require written consent for HIV tests. There are, however, rare exceptions. For example, a patient may arrive unconscious in the emergency room. Accessary medical procedures are provided to incompetent individuals, despite the usual requirement for consent. Prison inmates and people accused of certain crimes may be tested without consent.

The law of HIV testing is broadly defined by the right to "due process." The Fourth Amendment of the United f tates Constitution gives U.f. citizens the right to be free from "unreasonable searches." The California Constitution gives state citizens additional privacy protections.

Q: Can my insurance company require me to take an HIV test?

**A:** Yes. Life and disability insurance companies can require an HIV test without the usual requirement of counseling. It still is necessary to obtain your written consent. When you apply for insurance, you should read the contract carefully. Examine the policy to find out how the test results might be used. Not all health insurance companies will require an HIV test, but they usually obtain your medical records.

Q: Can my insurance company cancel my policy if they find out I have HIV?

A: Your insurance company may not legally cancel your policy or change your coverage on the basis of a positive HIV test. The insurance company always can cancel your policy if you do not pay required premiums. It also may cancel your policy if your application contained a material misrepresentation about your health.

Q: What can I do if I want to apply for new insurance, and the company requires an HIV test?

**A:** If you don't know your HIV status, you might want to get tested anonymously. Once you know your HIV status, you can decide if you want to pursue a particular insurance application. If a positive HIV test becomes part of your medical record, that information can be shared with other insurance companies.

Q: Can my sexual partners be told about my positive HIV status?



Karen Darnall

...the encrypted reporting system will make it impossible for public health officials to do an adequate job of containing the disease. A: In very limited circumstances, yes. First, your physician or surgeon must discuss the HIV test results with you. Then, your doctor must provide "appropriate educational and psychological counseling, that shall include information on the risks of transmitting immunodeficiency virus to other people." If you refuse to notify your spouse (or sexual partner or needlesharing partner), then your physician may notify these people without your consent. The physician, however, is not permitted to reveal your personal identity.

The physician may only tell your partner he or she may be at risk because of sexual activity or drug use. Your physician may refer your case to the county health department, to help with the education, counseling and notice requirements.

Q: Can my former partner sue me for transmitting HIV?

**A:** Yes. But your expectation of privacy is best if you ask your physician to contact the health department for confidential partner notification. If your partner hears gossip from friends or acquaintances, you are more likely to get sued.

If HIV notification is done through public health officials, the confidentiality of your test results is protected by California law. Health and /afety Code 121015(f) states that "no person shall be compelled in any civil, criminal, administrative, legislative or other proceeding to identify any individual who takes an HIV test." This law does not protect you from testimony that is not "compelled."

**Q:** What should I do if my positive HIV status is released without my consent?

A: If you believe your civil rights have been violated, you may file a civil action. You also can file a complaint with the California Department of Health. The agency must investigate your case and decide if any law has been violated. Consultation with an attorney may help you approach the problem objectively.

Q: If I reveal my positive HIV status to an attorney, does the information remain confidential?

A: Yes. California has created standards for attorney

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Advice in "Q and A on the Law" is not intended to replace legal counsel.

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Beyond AID/ Lifeline

# Public Health Fails American Women

By B. Poindexter

aren's<sup>\*</sup> husband worked in the Far East for the U.J. government. When he came home he gave her HIV. The bore three sons and all died before she did. He abandoned her when the disease was discovered. The watched each of their children die knowing she could do nothing to help them. Her only goal in life became staying alive to see all three of them buried together.

Many women I've talked to told me of husbands who went to their graves claiming nothing was wrong, knowing they had given their wives death sentences but refusing to tell them so they could seek medical help. Those women all asked me what they had done wrong to deserve such betrayal—that the men they loved did something this terrible to them and then said nothing. How does one rationalize that to them? They recoiled when I tried to shake hands for fear they would infect me—some did not even want to breathe in the direction of the one human being who was willing to sit in the same room with them.

Nationally, reports list HIV as the third leading cause of death among women in prime child bearing years of 25 to 44 years of age, and first among African American women for the same age group. At least one third contracted HIV through sex with a male and have died. The number is growing daily. The only way to stop it is to know who is infected. Women are becoming the most at risk members of American society. But through a united voice they have the power to prevent their own catastrophic end as a result of this epidemic. Women need to unite to push for partner notification of infected HIV carriers, a national HIV registry, and routine testing of pregnant women and babies. The question is, will they? Or will they listen to the same politicians who permitted the first failure of our public health system when it chose not to respond to contain and attempt to destroy the HIV virus when it initially surfaced?

We are losing our women, our babies, and our future as a functional society due to the current public health policies forced upon us by the government that already knows that this course has not controlled the HIV epidemic and leads to countless preventable deaths. Women and children of color are succumbing to this disease even faster than the population at large.



What this woman doesn't know could be to fatal to her and her baby...

...We are losing our women, our babies...Yet women as a group have failed to demand their government protect them...

\*names and certain details have been changed to protect individual privacy Yet women as a group have failed to demand protection from an element of society that may knowingly prey upon them. Do they care that an HIV+ male can infect them, destroy their lives at all levels, force them to watch their children die a horrible death followed by their own early, dreadful death? Or worse, have their children become orphans since the father will have surely died also. Most women's organizations have so far shown no signs of caring. Why are they not storming the halls of government demanding their right to live, to watch their healthy children grow to adulthood, and to be protected from a recognized threat to society? What could be a more urgent women's issue today?

In a society where sex before marriage is common and the main source of HIV infection for women is the men they sleep with, women need to be aware and take control of the public health system. If they don't, it could kill them. Women need to demand that all levels of government be able to identify the HIV virus carriers who threaten their lives and the lives of their children, both born and unborn. Women need to pressure the government to make a serious effort to reduce transmission by HIV carriers who knowingly expose women and other men to this virus either sexually and/or through needle sharing.

Because of politics and special interests, the American Public Health system is failing for a second time during this HIV epidemic. The first failure occurred when the Federal Government refused to follow proven epidemic control procedures during the height of the urban gay male epidemic. The result has been almost two decades of unabated HIV infection and death. Now, drug using and bisexual males are exposing women in the same uncontrolled manner with the same catastrophic results. And the Federal Government is taking the same no-action with the same predictable results.

Women, wake up! You have won the right to vote, to be treated as equals, to defend ourselves and to compete on an equal basis. Have you also learned not to die? You must use your votes, our economic power, our numbers, and your influence to compel our government to protect you and your children in the same manner it does when fighting any other epidemic. Rise up and live in an HIV free world you can help create by demanding the identication and monitoring of the HIV infected. It is your lives—and your children's lives. What are you going to do to protect yourselves and them?

B. Poindexter, in public health 25 years, specializes in disability, disability policy, and social AIQ/ research, and is a strong advocate of necessary prevention measures including identification of carriers and reasonable privacy where it does not seriously affect the health of others.

# Many Rape Victims Must Deal with Prospect of AID/

hen Annie Newton puts her twins to bed, there are no goodnight kisses to go along with nightly prayers. /he washes her hands before hugging the 10-year-old girls, and won't let them in the kitchen while she's cooking, for fear they might touch her blood if she cuts herself. Newton doesn't have AID/, and her lone HIV test taken less than eight years ago turned up negative.

But, like millions of other victims of sexual assault, she lives in fear of contracting the fatal disease that may not show up until years after initial contact. Although Newton knows her attacker had AID/, many rape victims can't even find out because privacy laws prevent some states from releasing the results of inmates' HIV tests or causes of death.

Newton's attacker recently died in prison after a long bout with AID, reminding the 39-year-old woman about her brutal ordeal and the possible consequences. Victim advocates say statistics on the number of women who contract HIV through rape are hard to come by.

A 1990 study published in the New England Journal of Medicine showed that less than 1 percent of victims surveyed contracted the disease through the attack. But that finding may be out of date, considering the disease's expansion and the increase in population and number of attacks over the last decade. And even if it is accurate, victims still are forced to think about the possibility.

"It's something that crosses every victim's mind," said Debbie Andrews, executive director for the Rape Abuse & Incest National Network. "You have to go through that struggle of not knowing for sure, even if the first test is negative." Liz Flowers, executive director of the Georgia Network to End / exual Assault, said the 1990 survey's figures probably weren't accurate because many women don't bother with testing. "Many attacks are by someone they know or a former sex partner," Flowers said. "That brings the fear level about HIV and AID/ way down, even though the risk is just as high."

That wasn't the case for Newton and other victims of Joseph Patrick Washington, who died in prison last October while serving a life sentence on charges of rape and murder in conjunction with five separate Augusta area attacks in the early 1990s. Washington forced the women into his car at gunpoint, drove to a remote location, shot the women and then raped and One witness testified that Washington had said he wanted to infect as many women as he could because his former girlfriend had given the virus to him.



Got a heroic HIV story? *Send your submissions to* 

the Editor by e-mail to ypover@pover.com or to Beyond AID/ Lifeline, 611 Pennsylvania Avenue, *f*E, #1600, Washington, DC 20003-4303 sodomized them, prosecutors said. Three women survived the shootings. Aewton was found nude and bleeding in a muddy ditch hours after her attack. Advocates say her chance of infection is greater than that of women who have normal sexual intercourse with an HIV-positive man because the brutal nature of the attack led to more blood contact. Washington had AID/ when he entered the state prison system. fome witnesses said he began his rampage soon after testing positive for HIV.

One witness testified that Washington had said he wanted to infect as many women as he could because his former girlfriend had given the virus to him. Georgia Department of Corrections spokesman fcott ftallings said that all incoming inmates are tested for HIV, but the results are not disclosed.

Many victims say such difficulty in obtaining information about their attackers' HIV status makes their ordeal even worse. "I'm constantly thinking that I may have survived the attack, but he might eventually murder me with HIV, and not knowing is just eating me up right now," said Kellie Greene, an Orlando, Florida, woman who was attacked in 1994. Greene, who has started the victim's advocacy group freaking Out Against Rape, said that she has sued Florida to get the medical records of her attacker, who was convicted, but has been told several times she can't access them due to privacy considerations.

"Why does he have any privacy rights?" Greene said. "He certainly disregarded mine." / everal state legislatures have recently passed legislation allowing victims access to such records. But in Georgia, it is up to the individual district attorneys to pass on the information to victims.

The specter of AID/ forces women to dwell on their attackers for much longer. "Rape produces posttraumatic stress syndrome, and if you can't put some distance between yourself and the attack, it will never go away," Flowers said. "And the longer possibility of AID/ just keeps hanging there, so will the effects of the attack."

∫uch has been the case for Deborah Baxley, another of Washington's victims. ∫he has been tested three times since the 1993 attack, and all have turned up negative. That doesn't stop Baxley from feeling her own mortality. "I might have escaped dying the first time, but there's no telling if it will come back around again."▲

### Beyond AID/ February Meeting



Robert Pacheco (R, CA Assembly, Walnut), author of our Baby AID/ bill, gave an enlightening talk on how he operates within the California Assembly and / enate. He discussed the need for bipartisan support and the efforts we in the community must make to see this bill into law. What was most encouraging was the personal commitment Assemblyman Pacheco has to protect the newborn. All of us felt that this was not politics for him, but a genuine concern to decrease the spread of HIV. He knows there will be political forces working against this bill—and he will not flinch.

JoElla Cudney, Pacheco's chief of staff, flew down from ſacramento to attend the workshop and meet with as many of us as possible. ſhe is the person overseeing the language of the bill and our primary contact in Pacheco's office. We could not have done better. ſhe is personable, understands the politics of this disease, and is also committed to protecting children in this epidemic. Four weeks ago JoElla contacted us (out of the blue) and asked how she could help—now we need to help her.

The decision at the workshop was to form three subcommittees to promote our legislation. We are taking volunteers now. George Mc/leely will oversee the subcommittees and each will have a chair(s).

1. Jponsorship committee—will focus on adding cosponsors to this bill, such as CMA, ACOG, IDAC, MADD, and all other medical, civic, public health, AIDJ service, organizations that will join in our effort. This will also include individual sponsors. The supportive letters will need to be sent to the various legislative committees that our bill passes through in the assembly and senate. We need the help of all nurses, public health officers, physicians, pharmacists, to get your organizations on board. The mission of Beyond AID/ remains the same stopping the spread of HIV.

Please R/VP to Cary Javitch

which committee you would

like to serve on and he will

forward your name to George

Mc/leely who is coordinating

this effort. If you would like to

contribute in other ways

please let us know.

2. Legislative committee. We will inform each legislator, (Assembly and Jenate, Democrat and Republican), informed with frequent updates on what is happening with Baby AIDJ. Hopefully we will have enough volunteers so that someone can be assigned to each legislator. If you have legislative contacts, please join this committee. Also, and very critical, persons with direct

contacts with Governor Gray Davis office are needed. We want the Governor's input from day



one—his suggestions, recommendations, concerns, and blessings. The Governor will be faced with the same political pressures from the AID/ activists that have intimidated legislators and health officials—but we have to believe that he will put public safety and the welfare of children above all that.

3. Media committee. This group will focus on journal articles, editorials, TV and radio. / cience is on our side. But we need to reach legislators, medical organizations, and the general public. If people are honestly informed on this issue they will join our efforts.

If we don't respond to halting the spread of this disease, who will? This entire effort should be led by public health officials—but it is not. Instead, it has taken a community response to wake up to the tragedy of this disease. We all share in the loss of loved ones and the suffering of those who are infected. Yet, when it comes to doing something about AID/ we get lost in the debates over rights and privacy and confidentiality. It is time we respond with a compassionate public health effort.

The mission of Beyond AID∕ remains the same—stopping the spread of HIV. ▲

*Note:* At the time of publicaiton, the CMA had signed on as a principle sponsor and critical compromises were pending.

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#### Capitol Watch

#### Federal Legislation

# **New Legislation**



Rep. Tom Coburn

Rep. Tom Coburn, (R-OK) is introducing his third bill to encourage state laws/regulations on reporting and partner notification, this time combined with incentives for states to test all babies whose mothers were not tested prenatally. Medical

studies to back up the proposal are cited.

These arguments are especially important in California because the latest thinking on legislation for this year will be to mimic this approach, linking newborn testing and routine prenatal testing (refusal permitted but no consent needed for testing) with changes in the law to facilitate providing identifying information on cases to local public health and to make partner notification easier.

The Women and Children's HIV Protection Act of 2000 aims to identify all babies at risk for HIV and link them and their mothers' to treatment to prevent HIV transmission or opportunistic infections associated with AID/. It would do this by providing funds to states with



Dr. Coburn introduces The Women and Children's HIV Protection Act of 2000.

To receive *HIV Updates* by mail or fax, contact Roland Foster in Rep. Coburn's office: roland.foster@mail.house.gov Tel 202-225-2701 Fax 202-225-3038 laws requiring that all newborns whose mothers have not been tested for HIV during their pregnancy would be routinely tested for HIV. One of the most promising victories in the battle against AID/ was the 1994 finding that administration of the drug ZDV during pregnancy and childbirth could significantly reduce the chance that a child of an HIV-positive mother would be infected.

Another study showed that using Caesarean section during birth, coupled with ZVD and avoidance of breast feeing, HIV transmission from mother-to-child can be nearly eliminated. A more recent study has found that even if treatment begins shortly after birth, transmission can still be considerably reduced.

Yet despite these medical miracles, more than five years later a significant number of women still are not tested for HIV during their pregnancy and many children are needlessly infected with an incurable, devastating disease that will prematurely claim their lives.

Nearly all new HIV infections among children are attributed to perinatal transmission of HIV. Approximately 6,000 to 7,000 HIV-infected women give birth each year and the number of female AID∕ cases continues to grow. By knowing the status of the woman or the antibody status of the newborn, future infections from breast milk can be prevented. ▲

All statistics from Centers for Disease Control and Prevention (CDC)

## Women's Group: *fenators* Putting Re-election Over *faving* Lives

The Independent Women's Forum (IWF) is accusing members of the U.J. Jenate of putting their own re-elections over saving lives from HIV/AIDJ. IWF is urging Congress to include HIV prevention in the federal AIDJ program, but the Jenate has ignored their pleas. Instead, "the focus of the Jenate reauthorization of the Ryan White CARE Act has focused almost entirely on providing AIDJ 'pork' to the states of several Jenators running for re-election this year," said Barbara Ledeen, IWF executive director of policy.

Ledeen cited several examples, including a clause of the fenate bill which guarantees preferential funding for fan Francisco. It would ensures that the city will continue to receive twice the amount of federal dollars per AID/ case as every other eligible city in the country. The noted another provision designed specifically to provide more federal AID/ dollars to Tennessee. Under the new "emerging AID/ community" program, a special set aside would be created by Beyond AID/ Lifeline Overlooked by the fenate is any mention of prevention... diverting a portion of CARE Act funding away from all states to provide funding primarily to seven cities, including both Aashville and Memphis. Also, the funding for the state of Vermont would be doubled under the fenate bill.

"Lost in the fight over AID/ pork, is the fact the a mere switch from AID/ based funding to one that included HIV would ensure fair funding for all states, cities and communities," Ledeen explained. "Also overlooked by the fenate is any mention of prevention, despite that fact that the Centers for Disease Control and Prevention has estimated that 40,000 new infections have occurred each year in the United ftates over the past decade—with the biggest increases among African Americans and women." Ledeen stated that "IWF is simply urging members of Congress to put saving lives over re-election tactics." ▲

Independent Women's Forum press release, 5/8/2000

## Doctors Warn Treatment / hould Not Replace Prevention

ach year, thousands of people in Los Angeles County are tested for sexually transmtted diseases (/TDs), including HIV, herpes, gonorrhea, and syphilis. A recent syphilis outbreak among gay men in the county has raised concerns about /TDs, particularly for teenagers who are becoming sexually active. About 1 million people contract herpes each year, and the American / ocial Health Association estimates that as much as 25 percent of all teenagers will contract some kind of disease, often without realizing it. Most /TDs do not have symptoms but can cause serious complications like cancer. Even couples in monogamous relationships can be at risk because of a past relationship. Doctors warn against becoming complacent regarding /TDs and sexual health. They note that just because there are some treatments for these diseases does not replace the need for prevention.

Reuters Health Information Services, 4/13/2000

### Visit our web site: www.beyondaids.org Email: BeyondAID/Inc@aol.com

# Meet Our Intern

student at the University of California, ſanta Barbara, Holly Leahy is well educated about the AIDſ crisis in this nation and the ridiculous politics surrounding it which jeopardize human lives. ſhe is a co-founder of Beyond AIDſ, Inc. and involved in several research and internships in the area of HIV/AIDſ health care. ſhe is also an EMT on an advanced life support ambulance, and has volunteered as an AIDſ companion. ſhe is painfully aware of the tragedy of this epidemic has seen countless people die from AIDſ.



Holly Leahy

#### HIV & The Law, continued from page 4

conduct in the Business and Professions Code. "It is the duty of an attorney to maintain inviolate the confidence, and at every peril to himself or herself to preserve the secrets, of his or her client." California law does not answer questions about warning people who are potentially at risk for being exposed to HIV. "Physicians and surgeons" and "public health officials" are the only ones authorized to do partner notification. Psychologists and "counselors" at law cannot legally divulge HIV status without written consent.



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